

EXPERIENCES OF LIVING WITH EPILEPSY

by

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DECLARATION

'I declare that: "**Experiences of Living with Epilepsy**" is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

I further declare that I submitted the thesis/dissertation to originality checking software and that it falls within the accepted requirements for originality.

I further declare that I have not previously submitted this work, or part of it, for examination at Unisa for another qualification or at any other higher education institution.'

Signature



21 January 2019

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Date

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To my Father and Mother – Thank you for all the opportunities you have provided me with and your ongoing mentorship and care.

To my Supervisors – Thank you for your patience, and all your support and guidance throughout the process of writing this thesis.

ABSTRACT

Approximately 50 million people worldwide and one in every 100 South Africans, live with epilepsy. The challenges of epilepsy are not limited to the physical manifestations of the disease i.e. seizures. Public perceptions of epilepsy contribute significantly to an individual's experience of living with epilepsy. Stigmatisation of epilepsy occurs worldwide and presents in varying forms. Enacted stigma refers to overt acts of discrimination against people with epilepsy and perceived (or "felt") stigma is the feeling of shame and fear of being stigmatised as a person with epilepsy. Epilepsy stigma is considered to be one of the most important factors that have a negative influence on people with epilepsy. There is a noticeable difference in the nature of epilepsy stigma between developed and developing countries, and even between communities within the same country. This difference suggests that epilepsy stigma is shaped by differences in education, cultural values, access to healthcare, quality of care and legal rules. There is very little research on epilepsy-associated stigma emerging from South Africa. The aim of this study is to describe the lived experience of living with epilepsy and the associated stigma. Following qualitative methods, using an ethnographic approach, 10 semi-structured interviews with people with epilepsy were conducted. The complexity of studying the subjective experience of stigmatisation lends itself well to this approach. Participants were identified through the Western Cape branch of Epilepsy South Africa and recruited from various communities in Cape Town, South Africa. Data was analysed using Braun and Clarke's (2006) principles of thematic analysis. The participants reported a broad range of subjective experiences and perspectives of living with epilepsy. Across all participants, the factors which played an impactful role on their lives was the social support they received, the public understanding of the community they lived in, the daily reminders of being "different" and living with the fear of not knowing when the next seizure will occur. By nature of this study's design, the findings from this study cannot be generalised to South Africa. However, this study offers a glimpse into the subjective experience of living with epilepsy from individuals residing in different communities in Cape Town, South Africa. The findings show a broad range of experiences which are mediated by external influences. The findings suggest a need for further research into the challenges people with epilepsy face across communities within South Africa.

KEY WORDS

Epilepsy; epilepsy associated stigma; perceived stigma; felt stigma; enacted stigma; stigmatisation; seizures; South Africa; qualitative study

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Chapter 1

Introduction

1.1 Background

1.1.1 What is Epilepsy?

Epilepsy is a neurological condition which can affect anyone, at any age. It transcends geographical, social, gender, age and racial boundaries (De Boer, Mula, & Sander, 2008). Eastman, a neurologist with a special interest in epilepsy, explains “epilepsy may be due either to physical disorders such as a lesion in the brain or to a genetic predisposition. The clinical hallmark of epilepsy is seizures. Seizures occur in many forms and most commonly result in an alteration or loss of consciousness” (R. Eastman, personal communication, 2 August 2014). Approximately 50 million people worldwide are living with epilepsy (Bandstra, Camfield, & Camfield, 2008). Of these, 80% are estimated to live in developing countries, with limited resources (Ahmad, 2011) which result in patients often going untreated (De Boer et al., 2008). It is estimated that a significant portion of this group resides in sub-Saharan Africa (Mushi et al., 2011) and that one in every 100 South Africans live with epilepsy (Keikelame & Swartz, 2013a).

1.1.2 What is Stigma?

Being stigmatised refers to a loss of status and social exclusion due to being deemed “different”. Erving Goffman’s (1963) theory of social stigma proposed that individuals tend to be stigmatised because they possess an attribute, behaviour or reputation that “deeply discredits” them in the eyes of the public, the so-called “normals”. The stigmatised are perceived as “undesirable” and “not quite human”, making them a valid target for discrimination and social exclusion. As such, the “normals” construct a discourse that explains the inferiority of the stigmatised individual, often imposing other unfavourable (possibly, untrue) attributes onto the stigmatised individual (Goffman, 1963).

1.1.3 What is Epilepsy-Associated Stigma?

The challenges of epilepsy are not limited to the physical manifestations of the disease, namely seizures. Public perceptions of epilepsy contribute

significantly to an individual's experience of living with epilepsy. Epilepsy-associated stigma results from misconceptions and a lack of accurate knowledge of the condition. Epilepsy-associated stigma consists of varying forms of stigmatisation, including enacted, perceived and courtesy stigma against people living with epilepsy. Enacted stigma refers to overt acts of discrimination against people with epilepsy ("PWE"). Perceived (or "felt") stigma is the feeling of shame and fear of being stigmatised as a person with epilepsy. Lastly, courtesy stigma is extended to persons closely associated with the person with epilepsy, where family or friends may feel a sense of shame or fear that they will be discriminated against as they have a child, sibling, parent or friend with epilepsy (Scambler & Hopkins, 1990). Stigmatisation of PWE occurs across all societies. It has been suggested that, while enacted stigma may be more common in developing countries, where the level of education and understanding about epilepsy may be less, in developed countries there is a much greater degree of perceived (or "felt") stigma (Baker, Brooks, Buck, & Jacoby, 2000).

Yet, even in many developed countries a lack of knowledge, negative attitudes and misbeliefs about epilepsy are still common. Jacoby, Gorry, Gamble and Baker (2004) conducted a study in the United Kingdom (UK) about the public perception of epilepsy. The study found that epilepsy was described as "a physical health problem" by 31% of participants, "a mental health problem" by 19%, "both a physical a mental health problem" by 34%, while 4% described it as "neither," and 11% said they did not know. In 2001 a survey conducted by the Epilepsy Foundation of America in the United States of America (USA) was administered to just under 20 000 American high school students. The results of the study revealed the following: 50% were uncertain if PWE could drive cars, could work or should have children. Fifty percent thought that people died from seizures, and 50% confidently believed epilepsy was contagious. Furthermore, 31% indicated that they would not date a person with epilepsy, and 63% believed that youth with epilepsy were, or might be, more likely to get bullied or picked on than others (Austin, Shafer, & Deering, 2002). Another large-scale community-based survey conducted in the UK found that PWE are perceived as retarded, frail, antisocial, hostile,

potentially violent, slow, and physically unappealing (Bandstra et al., 2008).

1.2 Research Question

1.2.1 My Interest in the Topic

The purpose of this study is to describe the lived experience of living with epilepsy and the associated stigma. I am curious about the concept of stigma, and more specifically the concept of stigma associated with illness. Why are people stigmatised for being “different” and why are some illnesses stigmatising and others not? My Honours project focused on epilepsy associated stigma in a community in Cape Town. I found that the participants with epilepsy faced stigmatisation and this had a negative impact on their lives. Responses from participants included:

"Before, I was busy with sports, the seizures are why I don't do it anymore, because I was afraid I get a seizure while I am busy with it" (Participant #3).

"they were scared to even be with me at the same time, even for an hour or so, they would just make it so obvious ... they would say like I need to be home, I need to get home ... that's why I've never had friends, I still don't ... other kids were nervous because they didn't know how to help me if I should have a seizure" (Participant #4).

"Some people treat me differently, it's like they feel sorry for me, some, where I stay, say to my family, I am so sorry for you, your child is epileptic, [People with epilepsy] can't do things like go to parties" (Participant #5).

"My brothers used to tease me ... call me names ... children at school did too ... also the neighbour ... I hardly have friends because of my sickness" (Participant #1).

"My aunt treated me like a child, she always handled me as a child, didn't let me work with adults and that, I had to go through a childish life" (Participant #2).

1.2.2 Gap in Research

Globally, there is an expanding field of literature on epilepsy-associated stigma and the negative ramifications thereof. Ann Jacoby, a leading researcher in stigma associated with epilepsy, has been a prominent voice in this field. It is clear from the literature that there is a noticeable difference in the nature of epilepsy stigma between developed and developing countries, and also between communities within the same country (Mushi et al., 2011). There are also significant differences in European countries on reported feelings by PWE about epilepsy-associated stigma. For example respondents in Netherlands and Spain reported fewer feelings of stigmatisation than respondents in Poland and France (Doughty, Baker, Jacoby, & Lavaud, 2003). Although stigmatisation of illness is acknowledged as a universal phenomenon we know very little about the cross-cultural distribution of stigma across countries (Pescosolido, Olafsdottir, Martin, & Long, 2008). Assumptions about this difference across communities and countries suggest that epilepsy stigma is shaped by differences in education, cultural values, access to healthcare, quality of care and legal rules, among other factors. There is very little research on epilepsy-associated stigma emerging from South Africa. Having found positive results from my Honours project, highlighting that epilepsy-associated stigma is present in the lives of PWE who resided in communities in the Western Cape, South Africa, I wished to explore, more deeply, epilepsy-associated stigma in PWE.

1.2.3 Research Objectives

This study aims to answer the research question: Do PWE from communities in Cape Town, South Africa, experience epilepsy-associated stigma? The primary objective of this study is to first describe the lived experience of living with epilepsy and to explore the associated stigma in PWE. These PWE will be recruited from communities in Cape Town, in Western Cape, South Africa. The second objective of this paper is to highlight reoccurring themes of epilepsy associated stigma across participants.

1.3 Literature Review

1.3.1 Contributing Factors of Epilepsy-Associated Stigma

People with epilepsy face stigmatisation and discrimination at multiple levels. At the institutional level PWE face employment restrictions. At the interpersonal level they face overt acts of discrimination while at the individual level they face negative perceptions of self. Epilepsy is unique in the level of stigmatisation it receives. Suggestions as to why epilepsy is more stigmatising than other chronic disorders include: symptoms are not familiar or understood, the disruption of seizures to social order, the label of being an “epileptic”, the perceived lack of “social value” of PWE and the lack of public understanding about the condition (Field, 1976; Reidpath, Chan, Gifford, & Allotey, 2005). Studies consistently support the opinion that better education correlates with greater social tolerance (Ahmad, 2011; Chomba, Haworth, Atadzhanov, Mbewe, & Birbeck, 2007; De Boer et al., 1994; Mushi et al., 2011; Ryan, Kempner, & Emlen, 1980). For example, enacted stigma is becoming increasingly uncommon in developed nations and well-informed communities, as public awareness and correct information are broadcasted into societies (Caveness & Gallup, 1980). However, perceived (or “felt”) stigma in these same communities continues to exist (Ahmad, 2011). Studies have shown that “felt” stigma tends to be far more debilitating than any enacted stigma on PWE (Ahmad, 2011).

1.3.2 Impact of Epilepsy-Associated Stigma

Many researchers have investigated the effects of epilepsy stigma on PWE. Global literature in this field shows that there is substantial evidence indicating that epilepsy stigma negatively affects PWE, albeit varying by degree and consequence (Bandstra et al., 2008; Fisher et al., 2000; Hermann, Whitman, Wyler, Anton, & Vanderzwaag, 1990; Paschal et al., 2007). Ahmad (2011) goes as far as to claim “Epilepsy stigma is considered to be one of the most important factors that have a negative influence on people with epilepsy. It is a commonly encountered global issue among people with epilepsy in all cultures. Epilepsy stigma may have deleterious effects on the patient’s life, more than the disease of epilepsy itself.” He has recognised epilepsy stigma as a major casual factor of psychosocial morbidity for PWE (Ahmad, 2011,

p.1). McQueen and Swartz (1995) conducted a study to investigate these psychosocial effects of stigma in a rural community in South Africa. They found PWE chose to conceal their condition due to perceived stigma (McQueen & Swartz, 1995). Scambler and Hopkins (1990) developed a “hidden distress model” of epilepsy in which they proposed that when diagnosed with epilepsy, people actively conceal both their seizures and their associated distress, which then results in more disruption of their lives than any enacted stigma would. Numerous studies have also demonstrated and highlighted how epilepsy stigma influences health-seeking behaviour, making PWE conceal their condition, delay in seeking care and making poor treatment and care choices (Keikelame & Swartz, 2013b; McQueen & Swartz, 1995; Mugumbate & Mushonga, 2013; Mushi et al., 2011).

Abroad, numerous studies have also indicated the negative psychosocial effects epilepsy stigma has on PWE. Fisher and associates (2000) conducted a survey with 1000 PWE in the United States of America investigating their perceptions and subjective experiences of living with epilepsy. Over a quarter of the participants reported being stigmatised due to their diagnosis. Other feelings reported were loneliness and shame and fear of reaction of others. Another community-based survey ($n=165$) revealed that over 40% of participants felt that the public had negative perceptions and reactions towards them due to their diagnosis while 41% felt that this contributed negatively to how they perceive their sense of self (Bandstra et al., 2008). In Mushi and associates’ study (2011) similar feelings were reported.

1.3.3 Management of Epilepsy-Associated Stigma

Not all PWE experience stigma (Baker et al., 2001; Jacoby, 1992, 1994; Jacoby, Chadwick, & Doughty, 2001). For those who do, there is a clear negative impact on their quality of life (QoL) and other life domains (Ahmad, 2011; Hermann et al., 1990). The overall aim for better management of epilepsy is to improve the “social value” of PWE and to prevent a diagnosis of epilepsy becoming an all-consuming social identity. Literature in the field writes about the positive impact pilot interventions and awareness campaigns have had on combating epilepsy stigma in communities, thereby supporting a

need to continue to promote de-stigmatisation campaigns around the world (Ahmad, 2011; Caveness & Gallup, 1980; De Boer et al., 1994). Literature has also indicated that there is a need to determine the nature and relevant features of stigma in order to improve de-stigmatisation campaigns (Carpio & Hauser, 2009; Rafael et al., 2010). Social stigma toward a person with epilepsy varies greatly between cultures and therefore needs to be interpreted and addressed within the sociocultural context of a community (Winkler et al., 2010) in order for effective, relevant, community-based interventions to be developed. Moreover, efforts to reduce stigma need to look at interventions targeting stigma at the institutional, interpersonal and individual level.

1.4 Importance of the Study

There is an urgent need to explore cultural specific social realities of PWE, and to improve their “social value” and social identity by addressing stigma and discrimination at all the levels at which it is experienced. In the context of South Africa, this is a highly relevant debate and also very complex. South Africa is a melting pot of cultural beliefs, and has a large socioeconomic spectrum. Therefore, the stigma a South African person with epilepsy faces will vary from one community to another, and exploring community specific social realities of PWE in South Africa is necessary to inform community relevant interventions to address stigma. The purpose of this research is to raise awareness of the potential stigmatisation PWE face living with epilepsy, and the possible impact this has on their life.

1.5 Research Methodology

1.5.1 Methodology

The aim of this study is to create an ethnographic record of the lived experience of individual people who are living with epilepsy. It will employ qualitative methods and follow an ethnographic approach to answer the research question: Do PWE from urban communities in Cape Town experience epilepsy-associated stigma? The study aims to analyse and describe the subjective experiences and perspectives of PWE. The objective is to provide information that can be used to guide future research.

1.5.2 Sampling

Participants will be purposefully sampled through the head of the Western Cape branch of the NGO, Epilepsy South Africa. Participants will be screened according to the following criteria: they must have been diagnosed with epilepsy, be over the age of 18, cognitively competent to participate and they need to be able to speak English.

1.5.3 Data Collection

Ethnographic research commonly involves the researcher being the primary data collection tool. For the purposes of this study, data will be gathered by myself via an informal, semi-structured interview. This method was chosen as it is the most appropriate method to gather information to answer the research question. A detailed motivation will be presented in Chapter 3. The interview will be voice-recorded using a recording function on the interviewer's cell phone and later transcribed. The participants will be asked to sign a consent form, confirming their willingness to participate and be recorded before the interview takes place.

Self-constructed questions will be developed for the interview. These questions will be developed using the guidance of items from standardised scales. These questions will be adapted to be open-ended for the interview setting and will aim to explore the experience of living with epilepsy and the associated stigma from the perspective of people with epilepsy. Table 3.1. in Chapter 3 includes a list of standardised scales which were consulted to draw up the interview questions.

1.5.4 Data Analysis

For the purposes of this study, data will be analysed via thematic analysis, following the principles that Braun and Clarke (2006) outlined in their paper, *Using thematic analysis in Psychology*. Following an ethnographic approach, thematic analysis codes the data into meaningful categories and aims to identify broader key themes in the data, which answer the research question.

Following the 6-step guide by Braun and Clarke (2006), I will complete the

following steps:

1. Become well acquainted with the data by listening to the recorded interviews and transcribing the interviews.
2. Create an initial list of ideas of interesting content from the interviews, generate codes for the itemised content and start to compress this data into defined categories.
3. All relevant data will be coded, sorted, and collated into broader themes.
4. Consider the broader themes that have emerged which answer the research question.
5. Further define and refine themes in the data in relation to answering the research question.
6. Once a full set of worked up themes and categories has been acquired that are relevant to the research question, the write up will start.

1.5.5 Write Up

The case studies in Chapter 5 will be written from a first-person perspective. Due to the subjective nature of data analysis in thematic analysis using an ethnographic approach, writing from a first person perspective allows a form of transparency about how the author may influence the research process and data analysis (Braun & Clarke, 2006). By using this method, I aim to acknowledge the active and subjective role I play in the collection, analysis and presentation of the data.

1.5.6 Limitations

The limitations were that a small group of participants were used and that I was only able to conduct one interview per participant.

1.6 Ethical Considerations

Ethics approval has been granted by the Ethics Committee of the UNISA Department of Psychology.

Participants will be given a printed consent form in English (see Appendix A). They will also be verbally guided through the consent form, and informed

upfront that interviews will be voice-recorded, and that their consent will be required. They will then be asked to sign, acknowledging their consent to participate in the study.

The participant will be informed that their participation is entirely voluntary, and that they are free to leave the interview at any stage if they no longer wish to continue. There are no foreseen risks or costs to the participant taking part in this study. The participants' identity and information will remain confidential and anonymous. If information revealed in the interviews indicates that the participant may wish to harm themselves, relevant parties will be informed.

1.7 Presentation

Chapter 1 of this dissertation provides a rationale for doing this study. It also paints an outline of the chapters to come. It gives a brief overview of the relevant literature, a motivation for the need to explore the topic and a simple outline of the research design.

Chapter 2 provides a comprehensive review of the literature on epilepsy-associated stigma and summarises the impact of epilepsy stigma has on PWE.

Chapter 3 will give a detailed account of the research methodology. It unpacks the planning and implementation of the data gathering and analysis process.

The pilot study chapter, Chapter 4, presents key themes which emerged from the raw data of the initial pilot study of seven participants. The findings are discussed in relation to published literature.

Chapter 5 presents three case studies, providing an in-depth account of the participants' lived experience of living with epilepsy and contrasts these findings with published literature.

Lastly, the final chapter, Chapter 6, will pinpoint key important findings from

this study and suggests ways to further explore this topic in meaningful ways. The limitations of the study are also included.

1.8 Conclusion

The aim of this study is to describe the lived experience of living with epilepsy and to explore the associated stigma in PWE. Epilepsy is a common neurological condition. It is estimated that one in every 100 South Africans are living with epilepsy. Yet, PWE are often faced with stigmatisation and discrimination. Epilepsy has been viewed as more stigmatising than other chronic disorders. Being stigmatised refers to a loss of status and social exclusion due to being deemed “different”. Epilepsy-associated stigma is a result of misconceptions and a lack of accurate knowledge of the condition. Global literature in this field shows that there is substantial evidence indicating that epilepsy stigma negatively affects PWE. Noticeable differences in the nature of epilepsy stigma between developed and developing countries, and also between communities within the same country have been reported. The purpose of this study is to describe the lived experience of living with epilepsy and the associated stigma.

This study will be employing qualitative research strategies. Its aim is to describe the lived experiences of people with epilepsy and follow an ethnographic strategy. Participants will be recruited from Cape Town, Western Cape in South Africa. Data will be gathered by semi-structured interviews, and the data will be analysed via thematic analysis.

Chapter 2

Literature Review

2.1 Introduction

Epilepsy is a neurological condition, which can affect anyone, at any age. Studies estimate that epilepsy affects almost 70 million people worldwide with the prevalence in low-and-middle-income (LMIC) countries being almost double that of in high-income countries (HIC) (Preux & Druet-Cabanac, 2005; Sanders & Shorvon, 1996). Throughout recorded history, dating back to approximately four thousand years ago, the lack of understanding about epilepsy has bred misconception and superstition about the condition, and as a result of inaccurate knowledge of the condition, PWE have been stigmatised, and continue to be stigmatised today. As a result, PWE are perceived by the public and themselves as having less “social value” and become socially excluded. Stigma exists on many levels, more specially, at the institutional, interpersonal and individual level. This chapter provides a clinical description of epilepsy and explores the literature that discusses what stigma is, why people with epilepsy are stigmatised and how this impacts on their lives.

2.2 Clinical Description of Epilepsy

Epilepsy is the fourth most common neurological condition characterised by unpredictable seizures. Epilepsy may be related to a physical disorder such as brain injury or to a genetic predisposition. The disease¹ is a spectrum condition with patients varying in seizure types and control. However, with that said, it is important to highlight that having seizures is not synonymous with being diagnosed with epilepsy. There can be other explanations for a seizure occurring that may exclude epilepsy as a diagnosis (Sirven & Shafer, 2013).

In 2014, the definition of epilepsy was revised by the International League

¹ epilepsy is now called a disease, rather than a disorder. This was a decision of the Executive Committees of the ILAE and the International Bureau for Epilepsy (Fisher, 2014; Fisher et al., 2014).

Against Epilepsy (ILAE). According to the revised definition of epilepsy: A person is considered to have epilepsy if they meet any of the following conditions:

Epilepsy is a disease of the brain defined by any of the following conditions:

- At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart.
- One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
- Diagnosis of an epilepsy syndrome.

Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or for those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years (Fisher, 2015 p. 130).

2.2.1 Classification of Seizures

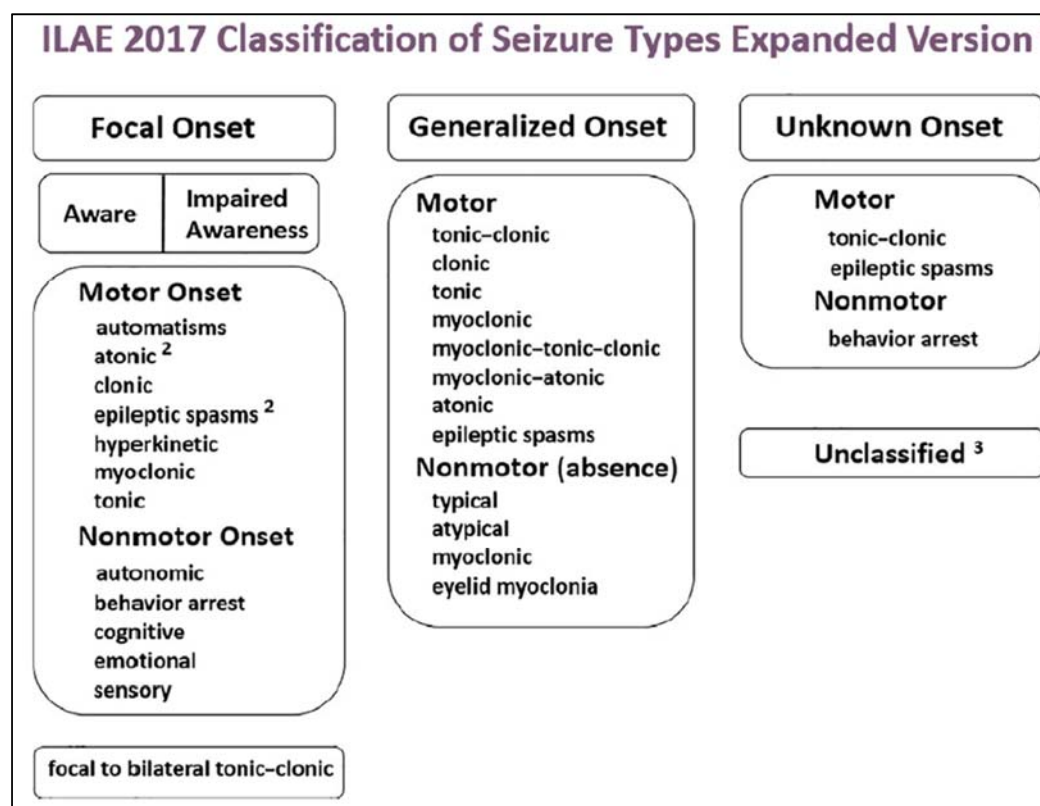
Given that seizures are (usually) a visible symptom² of having epilepsy, and have played a big role in influencing people's perceptions of epilepsy, dating back centuries (Temkin, 1971) and still today, it seems appropriate to give attention to seizures.

In 2017, the ILAE revised the classification of seizures (Fisher et al., 2017). Unbeknown to those unfamiliar with epilepsy, there are many types of seizures. Please see Table 2.1 for a comprehensive list. However, the type of seizure which is widely familiar, as it is often portrayed in popular media, is the generalized tonic-clonic seizure. During a generalised tonic-clonic seizure a person loses consciousness, his or her muscles stiffen, and jerking movements follow. This sequence of events could be, and often is, viewed as

² Not all parts of a seizure, or all seizure types, are visible. Every person with seizures will not have every stage or symptom of a seizure and seizures affect different people in different ways (Kiriakopoulos & Shafer, 2017).

a “violent action” to those unfamiliar with the clinical presentation of tonic-clonic seizures.

Table 2.1 ILAE 2017 Classification of Seizure Types. Retrieved from: Fisher (2017, p.534).



The characteristics of seizures vary: it can affect any part of the body, as the events that evoke the seizure occur in the brain. The location within the brain, and where and how far it spreads across the brain’s hemispheres all dictate the type of seizure which will occur (Schachter, Shafer & Sirven, 2014).

2.2.2 Triggers of Seizures

For the majority of PWE, seizures occur spontaneously with no clear triggering event. Rarely, however, seizures may be caused by an event. Commonly reported triggers include: 1) having seizures at a specified time during the day or night, for example, during sleep or when sleep-deprived; 2) seizures occurring in the presence of a high fever or illness; 3) exposure to flashing lights or specific visual patterns; 4) heavy alcohol use and drug use;

5) hormonal changes, for example, during a women's menstrual cycle; 6) poor diet, low blood sugar or specific foods (i.e. caffeine) and 7) use of certain medications (Schachter, Shafer & Sirven, 2013).

2.2.3 Prevalence of Epilepsy

Recent studies estimate that epilepsy affects almost 70 million people worldwide (Ngugi, Bottomley, Kleinschmidt, Sander, & Newton, 2010). This estimate is above that of the World Health Organisation's estimate of 50 million (Epilepsy, 2004). Ngugi and colleagues (2010) report that the original estimate of 50 million has been discredited due to the lack of precision in the studies which came to these estimates. These include methodological inconsistencies, lack of data in certain areas, and exclusion of those with inactive epilepsy³. Developing countries often have limited resources (Ahmad, 2011) that result in patients often going untreated (De Boer et al., 2008). The prevalence of epilepsy between developed and developing countries varies hugely. Studies estimate that prevalence in LMIC countries is almost double that of in HIC. More specifically, 4–7 per 1,000 persons in HIC (Sanders & Shorvon, 1996) and 5–74 per 1,000 persons in LMIC (Preux & Druet-Cabanac, 2005). It is estimated that a significant portion of this LMIC group resides in sub-Saharan Africa (Mushi et al., 2011). Furthermore, it is estimated that one in every 100 South Africans live with epilepsy (Keikelame & Swartz, 2013a).

2.3 What is Stigma

Being stigmatised refers to a loss of status and social exclusion due to being deemed “different”. Erving Goffman's (1963) theory of social stigma, defines stigma as an “undesired differentness”. He proposed that individuals tend to be stigmatised because they possess an attribute, behaviour or reputation that “deeply discredits” them in the eyes of *others*, the so-called “normals”. The “stigmatised” are perceived as “undesirable” and “not quite human”, making them a valid target for discrimination and social exclusion. As such, the “normals” construct a discourse that explains the inferiority of the

³ Inactive epilepsy (IE) refers to PWE who have had no seizures in the preceding 12 months.

stigmatised individual, often imposing other unfavourable (possibly, untrue) attributes onto the stigmatised individual.

The notion of stigma as a social phenomenon was first explored by the French sociologist Émile Durkheim in the late 19th century (Durkheim, 1938). He philosophised that segregating the concept of “normal” from “deviant” would result in a stigmatisation of the “deviant”, and in doing so bring social unity to the “normal” social group.

One frame of thought suggests that stigmatisation comes from a biologically based need to live in effective groups (Neuberg, Smith, & Asher, 2000). Those that deviate from group norms threaten the effective functioning of the group. Therefore, in order to protect and maintain the effective functioning of the group, they are ostracised. Others theorise that stigmatisation is rooted in a need to avoid danger (Stangor & Crandall, 2000). By highlighting characteristics that are considered to be threatening, a person who displays these is socially excluded in order to protect the group. Furthermore, there is a possibility that certain threats may be “hard-wired”. This assumption is drawn as some stigmas appear to exist universally, for example, stigmas toward facial disfigurement. Yet history shows that what is identified as a negative social identity differs between social groups and from one historical era to another (Crocker, Major, & Steele, 1998; Stangor & Crandall, 2000; Weiner, 1993). For example, stigmas around weight. Attitudes toward weight have differed over the centuries, and even today, are viewed differently from one social group to another (Jacoby, Snape, & Baker, 2005).

Lastly, stigma is viewed as a permanent label. Goffman (1963) argues that although stigmatised individuals may try to reclaim their “normal” status, this is unlikely to happen. At the very least their status may change to someone who was once “contaminated” and therefore they will remain “undesired”.

2.3.1 Stigma and Chronic Illness

Goffman (1963) presents three types of stigmas. Firstly, there is tribal stigma of race, nation and religion. Secondly, “blemishes of individual character”,

which encompass acts such as dishonesty, unemployment and addiction. Lastly, there are “abominations of the body”, which refers to health-related conditions and physical impairments and are the interest of this dissertation. Stigma has begun to be regarded by many as a fundamental component of chronic illness (Fabrega & Manning, 1972; Fabrega Jr, 1972; Field, 1976; Scambler, 1984; Scambler & Hopkins, 1990) and a measurable contributor to illness burden (Jacoby et al., 2005).

Research indicates that the act of stigmatisation may cause further health-related problems. Some studies have highlighted that people who are stigmatised often face a higher exposure to other health risk-factors (Krieger, 1990; Krieger & Sidney, 1996) and a lower access to protective factors such as adequate treatment and support (Major & O'brien, 2005; Meinardi, Scott, Reis, Sander, & World, 2001). In addition, stigma-related stress may further negatively contribute to a person's wellbeing (Cree, Kay, Tisdall, & Wallace, 2006; Flowers et al., 2006; Mays & Cochran, 2001). Link and colleagues (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989) suggest that stigma could possibly be a self-fulfilling prophecy⁴. Link and colleagues (1989) propose that through socialisation people adopt negative beliefs of being diagnosed with a disorder which has stigma attached to it. Therefore, when they receive the initial diagnosis they are immediately confronted by this stigma as they have already internalised a negative concept of what it means to be diagnosed with the disorder. Then, in fear of facing overt discrimination they adopt coping strategies which often involve secrecy and withdrawal. In this way, their “label” or diagnosis shapes their social behaviour. Yet, others (Jussim, Palumbo, Chatman, Madon, & Smith, 2000) suggest the concept of self-fulfilling prophecies in the maintenance of stigma is not a strong argument.

Why are some illnesses stigmatising and others not? The literature highlights

⁴ A self-fulfilling prophecy occurs when a person unknowingly causes a prediction to come true, due to the simple fact that he or she expects it to come true. In other words, an expectation about a subject, such as a person or event, can affect our behaviour towards that subject, which causes the expectation to be realized.

a few aspects that suggest an answer to this question. Field (1976) notes that there are important dimensions along which illness varies and which in turn impact the responses to that illness both by the person who is ill and those who interact with the ill person. He cites Fabrega and Manning (1972) who identify four points which are all interlaced and interacting: the duration of the illness, the prognosis of the illness, the degree of disability and the potential for self-degradation. Based on these dimensions, four main types of illness can be defined: short-term acute illness (e.g. “flu”), long-term non-stigmatising illness (e.g. “diabetes”), long-term stigmatising and mental illness (Field, 1976). In summary, Field proposes that illnesses which are likely to be stigmatising are those where 1) the symptoms are not well known, and are not understood, 2) the discomfort it causes in social interactions is severe (Albrecht, Walker, & Levy, 1982) and 3) the illness becomes a considerable part of the person’s identity. Reidpath et al. (2005) suggest that the perceived “social value” of the ill person is considered. However, Reidpath and colleagues also suggest that illness severity does not influence stigmatisation, and for simplification, the “normals” (Goffman, 1963) tend to group “deviant” individuals within broader “undesired” categories. By this definition simply being diagnosed with an illness will mean an inevitable loss in social value regardless of illness severity.

Many authors have also pointed out that illnesses which are stigmatised are often perceived to be the fault of the person who is ill (Albrecht et al., 1982; Crandall & Moriarty, 1995; Rush, 1998; Weiner, Perry, & Magnusson, 1988). Interestingly, the degree of sympathy and support for those with chronic illness is also affected by perceptions of causality (Menec & Perry, 1998; Weiner, 1993; Weiner et al., 1988). If the causality of a disorder is perceived as uncontrollable, sympathy and support toward the affected person is more readily prompted, whereas disorders that are perceived as controllable (often behaviour and mental disorders) and deemed the fault of the stigmatised individual, tend to prompt feelings of anger and avoidance.

A study by Muhlbauer (2002) aimed to analyse stigma types. They found that stigma was multifaceted and occurred both in public and private life domains.

She identified the following types of stigma: internalised, family-centred, direct personalised and indirect institutionalised. Internalised stigma refers to when a person “internalises” their feelings about being different and in turn perceives themselves to be different. Direct personalised or interpersonal stigma refers to when a person experiences being treated differently in their personal interactions. Lastly, indirect institutional stigma refers to when a person is treated differently within broader society, for example their interactions with the law or business.

If stigma is multifaceted, and all levels are interacting and impacting on one another, then it suggests that stigma needs to be addressed in its entirety and not only one component at a time if one is to effect meaningful change for people who are stigmatised.

2.3.2 History of Epilepsy-Associated Stigma

Epilepsy-associated stigma is a result of misconceptions and a lack of accurate knowledge of the condition. Throughout recorded history, dating back to approximately four thousand years ago, the lack of understanding about epilepsy has bred misconception and superstition about the condition. Common superstitions were that epilepsy was contagious, and associated with demonic possession, divine punishment and witchcraft. The history of epilepsy is both complex and interesting (Haynes & Bennett, 1992; Temkin, 1971). For an in-depth and detailed look into the history of epilepsy Oswei Temkin’s book, *“The Falling Sickness”*, first published in 1945, should be read.

Seizures, the clinical hallmark of epilepsy, have consistently captured people’s attention over time. Some of the earliest texts discovered which document the observation of a seizure date back to between 1000 B.C. and 2000 B.C. The earliest texts found are written in Akkadian⁵ (Temkin, 1971). One of the earliest texts found describes a person having what in the present

⁵ Akkadian is an extinct language that was spoken in the ancient region of Mesopotamia. (Present day regions of Iraq, Turkey and Syria).

day would be diagnosed as an epileptic seizure. The text explains that an exorcism was conducted to stop the seizure, which was said to be the result of satanic possession (Fulton, 1959; Temkin, 1971). Other texts dating back to this early period originated from ancient Egyptian medical texts, Babylonian (a region of ancient Mesopotamia) medical texts and the Babylonian Hammurabi code. Writings originating from Egypt and ancient Mesopotamia attribute the condition to evil supernatural causes (Magiorkinis, Sidiropoulou, & Diamantis, 2010).

The first discourse that disputed that epileptic seizures were caused by evil supernatural forces was found in a chapter of the Hippocratic Corpus (460-370 B.C.) entitled "On the Sacred Disease" (O'Leary & Goldring, 1976; Temkin, 1971). It correctly indicated that epilepsy was a disorder of the brain. Many consider this chapter to be one of the best-written chapters in the Hippocratic Corpus. Some authors claim that it provides a more accurate description of epilepsy than any other medical writings until the 17th century (Haynes & Bennett, 1992). However, despite Hippocrates correctly linking seizures to being a disorder of the brain, and not to divine intervention, the medical understanding of epilepsy was only formally recognised as a neurological condition at the end of the 19th century (Ahmad, 2011). Even through the 19th century and into the 20th century, many considered PWE to be mentally unstable and/or impaired and to have unscrupulous morals (Bear & Fedio, 1977; Benson, 1990; Waxman & Geschwind, 1975).

In summary, although epilepsy is widely understood today as a neurological disorder that can be controlled by medication and is more socially accepted than it has been in the past, negative attitudes, misbeliefs and superstitions about epilepsy are still present in many countries around the world today and continue to reinforce negative stereotypes and perpetuate stigma.

2.3.3 Understanding Epilepsy-Associated Stigma

Epilepsy-associated stigma is a well-understood concept in the literature, with many authors citing the plight of people with epilepsy globally. Throughout the centuries, and across cultures, people with epilepsy have been negatively

labelled and have been stigmatised (Temkin, 1971). As explored earlier in this chapter, Goffman (1963) claims that people are stigmatised because they possess an attribute, behaviour or reputation that “deeply discredits” them, and makes them “not quite human”. Authors suggest that stigmatisation is motivated by a biological based need to live in effective groups (Neuberg et al., 2000) or perhaps a need to avoid potential danger (Stangor & Crandall, 2000). Others suggest that some diseases are more stigmatising than other diseases (Albrecht et al., 1982; Crandall & Moriarty, 1995; Fabrega & Manning, 1972; Field, 1976; Reidpath et al., 2005; Rush, 1998; Weiner, 1993; Weiner et al., 1988) for the following reasons: 1) the symptoms of the disease are unfamiliar, and are not understood, 2) the severity of discomfort it causes in social interactions, 3) the degree to which the illness becomes a part of the person’s identity and the 4) perceived “social value” of the ill person. Let us take a closer look at these above points in the context of epilepsy.

Seizures are likely the basis for epilepsy stigma as they are visible, unfamiliar and tend to severely disrupt social context. Some question whether we are in fact “hardwired” to perceive seizures as a threat (Jacoby et al., 2005). Stagnor and Crandall (2000) indicate there is evidence that suggests some characteristics are possibly “hardwired” as potential threats. Possible evidence for this hard-wiring has been linked to seizures being described as “terrifying”. Seizures stir up fear due to their unpredictability, visibly violent presentation, uncontrollability, the unknown and their affront to societal order (Ablon, 2002; Bagley, 1972; Crocker et al., 1998; Jochim & Acorn, 2000; Jones et al., 1984; Trostle, 1997; Ziegler, 1982). This results in social exclusion of people with epilepsy in order to “protect” the larger group.

Goffman’s discourse claims that simply being diagnosed with an illness will mean an inevitable loss in social value regardless of illness severity, which other authors (Reidpath et al., 2005) have supported. A diagnosis of epilepsy has shown to be wrongfully attributed to a range of undesirable traits. Through the 20th century, the field of psychiatry referred to “the epileptic personality,”

an interictal⁶ syndrome thought to include a range of negative attributes. At the time, it was felt that intensive psychoanalytic therapy was the most appropriate treatment for this condition. This opinion was published in major journals in the 1970s (Bear & Fedio, 1977; Benson, 1990; Waxman & Geschwind, 1975). However, the link between this syndrome and epilepsy was strongly questioned and the range of behavioural features of the interictal personality disorder or "epileptic personality" is very rarely seen (Epilepsy, n.d.). Although the concept of the "epileptic personality" has ceased to have resonance scientifically, it has continued to enforce a social stereotyping in the public's attitudes toward people with epilepsy (Reis, 2001). They are seen as individuals who encompass all these undesirable traits merely as a result of having a diagnosis of epilepsy.

Lastly, literature shows that people with epilepsy tend to adopt the "sick role" and adopt a new identity of being "epileptic" (Link, 1987; Link et al., 1989; Scambler, 1984; Scambler, 1989; Scambler & Hopkins, 1986, 1990). This is likely through socialisation and "stigma coaches" which will be discussed in more detail, later in this chapter.

2.3.4 Types of Epilepsy-Associated Stigma

Different forms of stigma have been distinguished in the literature. As discussed earlier, Muhlbauer (2002) identified the following: internalised, interpersonal and institutionalised stigma (Muhlbauer, 2002). Scambler and Hopkins (1990) wrote specifically about an epilepsy stigma model. They proposed a new "hidden distress" model which, at the time of conception, was critical of the current orthodox viewpoint that assumed that the negative psychosocial consequences of living with epilepsy were only grounded in the negative attitudes and behaviour by the public toward PWE. His study demonstrated that a majority of participants did not feel stigmatised due to having experienced an incident of enacted stigma, but rather that their "felt" stigma often preceded any acts of discrimination against them, although the "felt" stigma was possibly reinforced by later acts of enacted stigma. Scambler

⁶ The word inter-*ictal* refers to the period between seizures.

and Hopkins (1990) made an important distinction between “enacted” and “felt” stigma. Enacted stigma refers to overt acts of discrimination against PWE, and “felt” stigma is the feeling of shame and fear of being stigmatised as a person with epilepsy. They made this distinction as they noticed that although many people viewed epilepsy as a disorder against which they felt prejudice, they found very little evidence of PWE actually experiencing direct acts of prejudice (Scambler, 1984; Scambler, 1989; Scambler & Hopkins, 1986, 1990). Jacoby highlights throughout her papers that as stigma is multifaceted, the different components should be dealt with simultaneously (Jacoby, 2008; Jacoby & Austin, 2007; Jacoby et al., 2005; Jacoby, Snape, & Baker, 2008).

2.3.4.1 Institutional Discrimination

Although institutional discrimination is not the focus of this dissertation, and therefore not discussed in depth, it is important to highlight all aspects of stigma as it should be mentioned that all the components interact and play a role in the lives of PWE. The most commonly accepted institutional discrimination that people with epilepsy face are driving restrictions. Globally, PWE are only permitted to drive a vehicle if they have been seizure free for a defined period of time (Fisher et al., 1994). Furthermore, certain employment is restricted for PWE, for example, admission to the armed forces, teaching, the police force, the fire brigade and prison services (Jacoby, 2012; Smeets, van Lierop, Vanhoutvin, Aldenkamp, & Nijhuis, 2007). Legal discrimination against people with epilepsy has been a recurring theme, which includes restrictions imposed on marriage and immigration which some developed countries only did away with recently, and which still persists in many countries (Jacoby, 2012). A study in the UK looking at insurance difficulties of people with epilepsy found that 62% of PWE reported difficulty getting insurance cover and 36% had been refused cover due to having a diagnosis of epilepsy (K. Jacoby & Jacoby, 2004). There is very little literature on this aspect of institutional discrimination against people with epilepsy. More research should be done looking at the restrictions placed on PWE at this level.

2.3.4.2 Enacted Stigma (Public Attitudes)

Even in many developed countries a lack of knowledge, negative attitudes and misbeliefs about epilepsy are still very common. In 2001 a survey conducted by the Epilepsy Foundation of America was administered to just under 20 000 American high school students. The results of the study revealed the following: 50% were uncertain if PWE could drive cars, could work or should have children, 51% thought that people died from seizures. Only 50% confidently believed epilepsy was not contagious, 31% indicated that they would not date a person with epilepsy and 63% believed that youth with epilepsy were, or might be, more likely to get bullied or picked on than others (Austin et al., 2002).

Jacoby and others (2004) conducted a study in the UK about the public perception of epilepsy. The study found that epilepsy was described as “a physical health problem” by 31%, “a mental health problem” by 19%, “both a physical a mental health problem” by 34%, 4% described it as “neither” and 11% said they did not know.

Another large-scale community-based survey conducted in the UK found that PWE are perceived as retarded, frail, antisocial, hostile, potentially violent, slow, and physically unappealing (Bandstra et al., 2008). In another European based study, looking at employers’ attitudes towards hiring, it was revealed that 44% reported that epilepsy was a health problem which would cause them major concern, as it was believed to result in more workplace accidents, frequent absenteeism, and that it could make other employees uncomfortable (Jacoby, Gorry, & Baker, 2005). Another study done in the UK suggested that social avoidance of PWE might be the result of fear of not knowing what to do if the person has a seizure (Robson, 2006).

In some developing countries in Africa, epilepsy stigma is shaped by traditional indigenous belief. Results from studies done in parts of Asia and Africa revealed that PWE are prevented from marrying, as a belief exists that PWE may commonly pass the condition onto their child (Mushi et al., 2011). Many superstitious beliefs about epilepsy are still present in the smaller rural

communities in Africa (Jilek-Aall, Jilek, Kaaya, Mkombachepa, & Hillary, 1997; Mielke, Adamolekun, Ball, & Mundanda, 1997). In a study in Tanzania conducted by Mushi et al (2011) it was found that the biomedical understanding of epilepsy was very limited in the community. Epilepsy was attributed to being possessed by the devil (or some supernatural force), effects of witchcraft and the revenge of an aggrieved ancestral spirit. A study conducted in Benin (Rafael et al., 2010) also revealed that an overwhelming majority of participants perceived epilepsy to be caused by supernatural forces. A study conducted in Zambia interviewed local police officers to investigate their knowledge of the causes of epilepsy (Mbewe, Haworth, Atadzhanov, Chomba, & Birbeck, 2007). The study revealed that 77% recognised epilepsy as a brain disorder, 20% as spirit possession, 13% as effects of witchcraft and more than 50% thought epilepsy to be contagious (Mbewe et al., 2007). A study of Zambian healthcare workers (Chomba et al., 2007) showed that 25% would not allow their children to marry a person with epilepsy, and 20% felt that PWE should not hold employment. In Cameroon, considerable ignorance, fear and superstition about epilepsy was also shown (Allotey & Reidpath, 2007). A study conducted in Brazil, showed significant levels of prejudice against PWE in regard to employment, social relationships and education (Fernandes, Noronha, et al., 2007; Fernandes, Salgado, Noronha, de Boer, et al., 2007; Fernandes, Salgado, Noronha, Barbosa, et al., 2007; Reno, Fernandes, Bell, Sander, & Li, 2007). A study in Laos, showed that 66% of study participants would not want their children marrying a person with epilepsy, and 33% would not want to share a meal with a person with epilepsy, 25% thought epilepsy had supernatural origins and 38% thought it was contagious (Tran et al., 2007). However, although not all developing nations hold superstitions beliefs, there is noticeably more prejudice shown than in developed countries where access to information is higher.

Studies consistently support the opinion that better education correlates with greater social tolerance. Furthermore, it should be highlighted that enacted stigma is becoming increasingly uncommon in developed nations and well-informed communities as public awareness and correct information are

broadcast into societies, thereby changing public attitudes towards PWE (Ahmad, 2011; Chomba et al., 2007; De Boer et al., 1994; Mushi et al., 2011; Ryan, Kempner & Emlen, 1980). However, “felt” stigma remains a pressing concern, as despite changes in public attitude epilepsy still induces great psychiatric distress in PWE, and this is even more marked than in other stigmatising disorders like AIDS and mental health disorders (Bagley, 1972; Baumann, Wilson, & Wiese, 1995; Pryor, Reeder, & Landau, 1999; Watson, Ottati, & Corrigan, 2003). This is possibly due to the “visible” nature of having seizures.

2.3.4.3 Perceived or “Felt” Stigma

The Scambler and Hopkins’ model of looking at the psychosocial impact of epilepsy acknowledges three processes with regard to experiencing “felt” stigma (Scambler, 1984; Scambler, 1989; Scambler & Hopkins, 1986, 1990): Firstly, the initial diagnosis. When a patient is first told that he or she has epilepsy, there is an immediate negative assumption made by the person with epilepsy. They are immediately confronted with the stigma and perceive themselves to now be “socially undesirable” and it invokes fear of experiencing direct discrimination (or enacted stigma). As Link (1987) suggests, this is through a process of socialisation, prior to diagnosis (Link, 1987; Link et al., 1989). Scambler (2011) proposes that they label themselves with a new “epileptic” identity, and understand themselves to have a new identity with the disorder (Scambler, 2011). As Field suggests, this idea of a disease becoming part of identity is stigmatising as it “separates” the individual from the group (Field, 1976). Secondly, as a result of the fear of experiencing enacted stigma, and the threat of being socially “discredited”, PWE actively conceal their diagnosis from others (Scambler, 1989; Scambler & Hopkins, 1990). Thirdly, the act of concealment becomes much more disruptive of their lives, as they live in continual fear of experiencing enacted stigma (Scambler, 1989; Scambler & Hopkins, 1990). In addition, the act of concealment often results in poorer treatment management and ultimately negatively impacts on quality of life of the person with epilepsy (Scambler, 2004). Scambler (2011) later revisited this model and concluded that it continues to give a credible explanation of epilepsy stigma. Although not

everyone with epilepsy fits into this “hidden distress” model, a large majority do, even some who have infrequent seizures or are seizure free (Scambler, 2011).

A survey was conducted (Fisher et al., 2000) with 1000 PWE in America to find out their perceptions and subjective experiences of living with epilepsy. Over a quarter of the participants reported being stigmatised due to their diagnosis. Other feelings that were reported were loneliness, shame and fear of reaction of others. Another community-based survey (n=165) revealed that over 40% felt that the public had negative perceptions and reactions towards them due to their diagnosis and 41% felt that this contributed negatively to how they perceive their sense of self (Bandstra et al., 2008; Paschal et al., 2007). In a study by Mushi et al. (2011) similar feelings were reported. Participants reported they felt shame, fear of rejection, loneliness and anxiety. This supports Scambler and Hopkins’ original earlier findings (Scambler & Hopkins, 1990).

Jacoby and colleagues (Baker et al., 2001; Jacoby, 1992, 1994; Jacoby et al., 2001) have conducted several studies in developed countries, across a spectrum of patients who were either seizure free and or experienced well-controlled seizures. Their studies revealed a linear relationship between epilepsy severity and “felt” stigma. At initial diagnosis a large portion of patients reported that they feared they would be treated differently. However, at a 2-year follow up only a small minority of those who were seizure free, indicated that they continued to feel stigmatised. Yet, half the group of those with continuing seizures, continued to feel stigmatised. Other authors have said that this linear relationship between epilepsy severity and stigma is mediated by other factors such as perception of limitations, education (Ryan et al., 1980), both professional and informal support (Suurmeijer, Reuvekamp, & Aldenkamp, 2001) and medication side-effects (Baker, Jacoby, Buck, Stalgis, & Monnet, 1997). These confounding factors may explain why people who have well controlled seizures still experience “felt” stigma.

The role of the family, or other influential persons such as teachers, and healthcare workers, is a key component to “felt” stigma (Schneider & Conrad, 1980). Their attitude toward the diagnosis informs the patient’s perception of receiving the diagnosis, in addition to the broader public’s perception (Link, 1987; Link et al., 1989). These negative attitudes will be “learnt” by the person with epilepsy and internalised. These “stigma coaches”, a term coined by Schneider and Conrad (1980), impose their perceptions onto the PWE who then internalise these feelings.

The most prominent dynamic is between a parent and a child who has epilepsy. The parent is known to try to “overprotect” the child as a result of their diagnosis and in doing so instils a dependency in the child on the parent (Schneider & Conrad, 1981; Williams et al., 2003). The child adopts an identity of being chronically sick (Jacoby, 2008). This “overprotection” of the child leads to a parent limiting the actions of the child in an attempt to “protect” him or her. Youths with epilepsy have been shown to have lower self-esteem and higher rates of depression and anxiety (Baker, Spector, McGrath, & Soteriou, 2005). These restrictions then feed into adulthood and the person with epilepsy continues to limit themselves as a result of their childhood conditioning (Jacoby & Austin, 2007). This is seen in a study by Collins and colleagues where the adult participants describe feeling: less valuable, less adaptable, less dependable, less mature, less stable, less able to cope, less successful and less well-adjusted than the general population (Collins, Taylor, & Skokan, 1990). These feelings are a product of their internalisation of a “chronically ill” identity and adoption of the “sick role”.

Other studies have showed that this adoption of the “sick role” is further reinforced by “stigma coaches” (Schneider, 2009) such as parents and even healthcare workers whose advice was to put restrictions on the daily activity of PWE (Allotey & Reidpath, 2007). Beran and colleagues (Beran, Frith, & Harris, 1992; Beran, Jennings, & Read, 1981; Beran & Read, 1983) examined the attitudes of doctors in developed countries treating people with epilepsy and found that negative attitudes were also prevalent among doctors. Another study also found that a group of psychologists and social workers still

supported the idea of the epileptic personality (De Boer et al., 1994). However, more recent studies showed that after the implementation of professional education programs, the attitudes of healthcare workers improved (Caveness & Gallup, 1980; De Boer et al., 1994). Several researchers (e.g. Atadzhanov, Chomba, Haworth, Mbewe, & Birbeck, 2006; Chomba et al., 2007; Fernandes, Noronha, et al., 2007) examined the knowledge, attitudes, and beliefs in Zambia. The studies found that higher levels of accurate knowledge were more common in those who had graduated more recently. Keikelame, Hlls, Naidu, de Sá and Zweigenthal (2012) explored perceptions of doctors working in primary care settings in Cape Town, South Africa. Their analysis revealed that epilepsy is poorly managed in South Africa, and that the lack of attention to epilepsy management is a serious concern which, in some instances, has led to violations of health rights.

“Felt” stigma has shown to be far more debilitating than any enacted stigma (Ahmad, 2011). Hermann et al. (1990) showed that “felt” stigma was a key predictor in ascertaining the quality of life in PWE, with psychological distress, loneliness and adjustment following it in importance. This gives credence to the notion that the social reality of experiencing epilepsy-associated stigma, over the clinical reality of having epilepsy, is the burden associated with the diagnosis.

As the next section explores, different types of stigma, and different domains within the types of stigma, are experienced differently across cultures. It is therefore necessary to identify what the knowledge gaps, and discriminatory practices are within different communities and address it accordingly.

2.4 Cross-cultural Differences

It is clear from the literature that there is a noticeable difference in the nature of epilepsy stigma between developed and developing countries, and also between communities within the same country. Assumptions about this difference indicate that epilepsy stigma is shaped by differences in education, cultural values, access to healthcare, quality of care, and legal rules, among

others. This different presentation and severity of enacted and “felt” stigma paint very different pictures of living with epilepsy depending upon one's community.

In the developed nations superstitious belief is no longer accepted, but other misconceptions still exist as explored earlier in this chapter, whereas in the developing world superstitious belief is still rife. For example, a qualitative study conducted in Zambia by Baskind and Birbeck (2005) found that traditional healers believe that witchcraft is the main cause for epileptic seizures and treatments involve the use of plant and animal products. Though these supernatural explanations for epilepsy are no longer accepted in developed countries, they are still dominant in some of the resource-poor countries. Mushi et al. (2011) suggest this difference could be directly related to the level of education and access to health resources in the community. Mushi et al. (2011) contrast their study with another study conducted by Winkler et al. (2010) in a different community in Tanzania, which found that the majority of participants knew epilepsy to be caused by biomedical factors. Mushi et al. (2011) suggest this difference in knowledge around the disorder lies in the context of the community. The one area has an epilepsy clinic that provides education and awareness about the disorder, whereas in the smaller rural community people rely on traditional and spiritual healers for treatment and medical knowledge. Interestingly, a study involving people of Pakistan origin living in a community in the UK, found that even though the participants were familiar with the western biomedical model and understanding of epilepsy, their religious interpretations of epilepsy were still more acceptable to them (Ismail, Wright, Rhodes, & Small, 2005; Rhodes, Small, Ismail, & Wright, 2008).

Furthermore, in some communities there is an added burden where stigma extends beyond the person with epilepsy. In Chinese cultures the concept of “courtesy stigma” is prominent, where the family fears disgrace of the whole family as a result of having a member of the family with epilepsy (Kleinman et al., 1995). In this case, PWE are kept at home and kept secret.

Keikelame and Swartz (2013a) highlight that, in South Africa, there is a difference in cultural interpretations and understandings of epilepsy throughout South African communities and therefore different forms of stigma are present in communities (Keikelame & Swartz, 2013a).

2.5 Psychosocial Impact of Epilepsy-Associated Stigma

A diagnosis of epilepsy goes beyond a clinical diagnosis as the person encompass a new social identity of being “epileptic”. Global literature in this field clearly states that there is substantial evidence indicating that epilepsy stigma negatively affects PWE to varying degrees. It is also clear that this impact is strongly correlated with seizure control, yet is mediated by factors such as education, social support, and personal attitudes. Ahmad (2011) notes that epilepsy stigma is a global issue and that the stigma can have a more negative impact on the patient than epilepsy itself. A number of global studies have been done to provide evidence for this statement (Allotey & Reidpath, 2007; Baker et al., 2001; Baker et al., 2005; Collins et al., 1990; Hermann et al., 1990; Jacoby, 1992, 1994; Jacoby et al., 2001; Jacoby & Austin, 2007; Schneider & Conrad, 1980).

The following domains which are affected by epilepsy stigma are repeatedly reported on in the literature, they include: quality of life, marital status, employment status, education level, depression level, psychiatric level and anxiety level. The severity of impact is highly correlated with the frequency of seizures.

2.5.1 Quality of Life

There is a concern that the construct of Quality of Life (QoL) is not standardised through the literature (McLaughlin, Pachana, & Mcfarland, 2008), therefore making it difficult to summarise the measures that are conveyed by QoL. In regard to the psychosocial impact epilepsy stigma has on PWE, the following has been reported to be negatively impacted upon: self-esteem, social activities, family dysfunction, sleep impairment, access to adequate treatment, exposure to additional health-risks and quality of life (Ahmad, 2011).

In 1995 McQueen and Swartz conducted a study to investigate these psychosocial effects of stigma in a community in South Africa. They found PWE chose to conceal their condition due to “felt” stigma. Numerous studies have also demonstrated and highlighted how epilepsy stigma influences people with epilepsy’s health-seeking behaviours. Studies have revealed how stigma has lead them to conceal their condition, delay in seeking care and making uninformed and poor treatment and care choices (Keikelame & Swartz, 2013a; McQueen & Swartz, 1995; Mugumbate & Mushonga, 2013; Mushi et al., 2011).

Newton and Garcia (2012) wrote a paper reviewing the literature on the treatment gap in epilepsy. The treatment gap is defined as the number of PWE who are receiving no or inadequate anti-epilepsy drug therapy. They point out that epilepsy stigma is one of the obstacles that need to be overcome in order to bridge the large treatment gap for epilepsy in low-income countries. They make reference to studies conducted in rural Kenya and Ethiopia, which indicate that in rural communities, where access to primary healthcare is poor, PWE will consult traditional healers. Therefore epilepsy will be explained and treated within the healer’s traditional religious and cultural beliefs (Newton & Garcia, 2012).

2.5.2 Marital Status

The number of PWE who are reported to be unmarried in comparison to people without epilepsy is far higher. One of the highest reported unmarried rates for PWE is almost 60%. Public perception of PWE plays a role in this (Ahmad, 2011).

2.5.3 Employment Status

The employment rate of PWE is very low. This has been suggested to be a result of employers’ resistance to hiring PWE due to perceived safety and difficulties they foresee in the workplace, and perceptions of competence (Ahmad, 2011).

An unpublished Master’s dissertation looking at employers’ perceptions in

South Africa revealed that the employers did not have negative perceptions of employing PWE. However, there is a suggestion that social desirability bias may have skewed results (Kanhema, 2012).

2.5.4 Education Level

The education level of PWE is very low. The situation is worse in communities where PWE are actively held back from going to school as result of “courtesy stigma” (family being ashamed) or where PWE are considered mentally impaired. In some circumstances parents are overprotective and fear for their child’s safety and therefore hold them back. The above cases refer to PWE who are mentally competent and are held back due to epilepsy stigma. In some circumstances PWE do in fact suffer from cognitive impairment, either as a result of physical abnormalities or due to side effects of anti-epileptic drugs. This in turn leads to PWE having lower incomes (Ahmad, 2011; Baker et al., 1997).

2.5.5. Mental and Psychiatric Health

Depression and anxiety are major co-morbid problems in PWE, with prevalence sitting at 20-55% for depression and 10-25% for anxiety. It is suggested that depressive episodes suffered by PWE could be the result of the many social struggles PWE face due to epilepsy stigma and the unpredictable nature of seizures. It has been reported that there is a higher suicide rate in PWE in comparison to people without epilepsy (Ahmad, 2011).

2.6 How to manage Epilepsy-Associated Stigma

Not all PWE experience stigma; however, for those who do there is a clear negative impact on their QoL and other life domains. The overall aim is to improve the “social value” of PWE and stop the diagnosis of epilepsy becoming a social identity.

Literature in the field writes about the positive impact pilot interventions and awareness campaigns have had on combating epilepsy stigma in communities, and therefore there is a need to promote de-stigmatisation campaigns around the world (Ahmad, 2011). Literature has also suggested

that there is a need to determine the nature and relevant features of stigma in order to improve de-stigmatisation campaigns (Rafael et al., 2010). Social stigma toward PWE varies greatly between cultures and therefore needs to be interpreted and addressed within the sociocultural context of a community (Winkler et al., 2010) in order for effective, relevant, community-based interventions to be developed. Moreover, intervention efforts to reduce stigma should be targeting stigma at the institutional, interpersonal and individual level.

The World Health Organisation (WHO), International Bureau of Epilepsy (IBE) and the International League Against Epilepsy (ILAE), launched a collaborative global campaign against epilepsy called “Out of the Shadows” in 1997 to educate people about epilepsy in order to promote positive attitudes toward PWE and to minimise epilepsy stigma (Diop, De Boer, Mandlhate, Prilipko, & Meinardi, 2003). This project has now been taken a step further by looking at developing culturally appropriate approaches to minimise epilepsy stigma and discrimination against PWE by devising a relevant cross-cultural theoretical model to combat epilepsy stigma (Carpio & Hauser, 2009).

The popular media (films, books) have contributed to the negative image of PWE by portraying them as seriously flawed fictional characters (Kerson & Kerson, 2006) and it will be necessary to reverse this view. In this regard, popular and respected public figures who have epilepsy and are prepared to publicly reveal this are increasingly becoming powerful advocates for PWE (Engel, 2013).

It is also recognised that the medical community is not exempted from the social process of stigmatisation, and poor public health infrastructure and medical services contribute to the negative image of PWE (Baskind & Birbeck, 2005; Keikelame et al., 2012). As discussed earlier, studies have shown that healthcare workers can act as stigma coaches and reinforce negative perceptions. Traditional healers also play an important role in the management of epilepsy as many PWE in low-income countries consult traditional healers, either alone or in addition to biomedical health services

(Christianson et al., 2000). This is understandable as there are more traditional healers than biomedical practitioners in rural areas, and they are therefore more accessible (Newton & Garcia, 2012). This is very relevant to the South African context where there are approximately 100 000 traditional healers and where 80-85% of the population seek care from traditional healers (Keikelame et al., 2012). Attempts are being made to liaise with and connect the two systems to the benefit of PWE (Kendall-Taylor, Kathomi, Rimba, & Newton, 2008). This should be an area of focus to develop ways for traditional healers and biomedical doctors to work together in the management of epilepsy.

We need to reduce existing treatment gaps. Public information on epilepsy should be available and understandable if the health literacy of a community is poor (Keikelame & Swartz, 2013a). Public health messages should include, explaining what epilepsy is, dispelling community myths about epilepsy, educating people on what to do if they encounter someone having an epileptic seizure, and informing people where to seek care and support should they have epilepsy. A successful conjoint intervention effort, in an African community, including both public education and comprehensive treatment programmes was shown to alter attitudes to epilepsy. The intervention was found to reduce rates of traditional beliefs, decrease fears, and increase community acceptance of people with epilepsy (Jilek-Aall et al., 1997). However, the attitudinal changes were not maintained long-term, which suggest that eradicating stigma is a highly complex process.

We need to address poor coping strategies in PWE and support interventions to develop healthy coping skills. We need to challenge negative assumptions that PWE have of themselves and to build confidence and self-esteem in PWE. A study by Funderburk, McCormick, and Austin (2007) found that a person with epilepsy's attitude toward epilepsy predicted their mental health outcomes, and suggested that a positive attitude toward their diagnosis may improve a poor self-concept. Furthermore, we need to strengthen and grow self-help groups and social networks and stress the importance of educating their families and their wider social networks too.

Finally, the psychology of stigma needs to be better understood in order to address it more effectively (MacLeod & Austin, 2003; Trostle, 1997) and we need to explore the cultural specific social realities of PWE, and the ways these can be improved.

2.7 Conclusion

Epilepsy is unique in the high level of stigmatisation it receives. Suggestions as to why epilepsy is more stigmatising than other chronic disorders include: symptoms are not well known or understood, the disruption of seizures to social order, the label of being an “epileptic” and assuming a “sick role”, the fear of witnessing seizures, the perceived lack of “social value” and the lack of public understanding. People with epilepsy face stigmatisations and discrimination at multiple levels: at the institutional level PWE face employment restrictions, at the interpersonal level they face overt acts of discrimination and at the individual level they face negative perceptions of self. The life domains which are affected by epilepsy stigma include: quality of life, marital status, employment status, education level, depression level, psychiatric health level and anxiety level. The severity of the social and personal impact of epilepsy on the individual is highly correlated with the frequency of seizures. Not all PWE experience stigma; however, for those who do there is a clear negative impact on their QoL and other life domains. There is an urgent need to explore culturally specific social realities of PWE and to improve their “social value” and social identity by addressing stigma and discrimination at all levels. In the context of South Africa, this is a highly relevant debate and also very complex. South Africa is a melting pot of cultural beliefs and has a large socioeconomic spectrum. Therefore, the stigma a person living in South Africa with epilepsy will face will vary from one community to another, and one person to another. Exploring community specific social realities of PWE in the context of South Africa is imperative to inform community relevant interventions to address stigma.

Chapter 3

Research Methodology

3.1. Introduction

The aim of this study is to describe the lived experience of living with epilepsy and the associated stigma. PWE had been identified by the Head of the Western Cape branch of Epilepsy SA. Following a qualitative method, using an ethnographic approach, an initial pilot study was conducted which involved seven participants, thereafter an additional three people with epilepsy were recruited and more in-depth interviews were conducted. This chapter will discuss the research design, reasons for the research design, and further detail regarding the study population, sampling, data collection methods, data analysis methods and informed consent process.

3.2 A Qualitative Method: An Ethnographic Approach

Ethnography first emerged as a research style within the discipline of anthropology. Its focus is to provide insights and descriptions of the lives and practices of various cultures (Kahn, 2011). Its methods employ the researcher as the primary tool of data collection; the researcher gains insights and collects data through first hand methods (LeCompte & Schensul, 2010; Murchison, 2010). This is why critics of qualitative methods criticise the scientific rigor or objectiveness of the data generated. Qualitative research methods have long been criticised. Critics of qualitative research raise concerns of qualitative methods being subjective, and therefore, biased, and often small scale (Anderson, 2010). From an ethnographic viewpoint, the complexity of human lives and social interaction cannot be gathered and analysed in a controlled environment, and a rigorous ethnographic approach, when used to answer an appropriate research question, can be a powerful and insightful method of research (Murchison, 2010).

There are six characteristics of an ethnographic strategy. They are as follows:

1) it is not conducted in a laboratory, 2) it uses face-to-face interaction with participants, 3) it provides an accurate representation of participants' perceptions, 4) it employs inductive, interactive, and recursive data collection

methods to develop cultural specific theories, 5) it is sensitive in that human behaviour is contextualised within socio-political and historical domains, and 6) it frames all responses within a cultural context (LeCompte & Schensul, 2010). Ethnographers are “participant-observers” in data collection. This term, acknowledges the interactive role an ethnographer plays in data collection. This term also highlights the comparison between more traditional research methods where the researcher is often detached from data collection, for example, with the administration of surveys. The involvement of ethnographers in the process and their interactive strategy raises concerns for some, namely that there is not sufficient objectivity, replicability and ethics. However, there are methods to present data in a more objective and transparent manner that counter-balances the researcher’s direct involvement in data collection. For example, comparing results with other projects exploring the same research question, acknowledging the interviewer’s influence over the research process, and presenting as much raw data as possible. Ethnographers acknowledge these criticisms of this research approach and take steps to attempt to counteract the lack of objectivity in these methods. Yet it is also clear, that the depth and richness of information that can be collected via an ethnographic approach is distinct from more traditional research methods (Murchison, 2010). Ethnography can be a more suitable and fruitful strategy to uncovering and understanding the complexities of human behaviour, thoughts, feelings, interactions and perceptions.

The research approach of this study was selected as it will generate an in-depth understanding of the lived experiences of people living with epilepsy. Human behaviour, perceptions and emotions are not static, but are dynamic and complex. Individuals’ subjective experiences of the world are shaped by the interaction of external and internal factors. To be able to fully explore and represent a person’s lived experience, the implicit – their body language, what is not said, and choice of words, is equally as important as the explicit – what is said. This approach allows us to represent a person’s behaviour, feelings and environment in as naturalistic a context as possible. Stigmatisation is a uniquely different experience for each individual as it is mediated by factors such as cultural values, education and legal rules, and

therefore an ethnographic approach to explore and record a person's subjective experiences and perceptions is an appropriate method to employ.

3.3 Pilot Study

The initial pilot study was my Honours research project. Pilot studies in qualitative research are beneficial in the context of ethnography as they enable the researcher to become familiar with fieldwork. In general, pilot studies enable the researcher to gather background information which can be used to guide the logistics and questions of the next stage of the research (Janghorban, Latifnejad Roudsari, & Taghipour, 2014; Kim, 2011). In an attempt to counteract my subjective influence over the interpretation of the data, I have endeavoured to present a large portion of the raw transcribed data in Chapter 4.

3.3.1 Population and Sampling

The pilot study interviewed PWE who were employed at the protective workshop of the Western Cape branch of Epilepsy South Africa (SA). Epilepsy SA is a non-governmental non-profit organisation, which aims to improve the lives of PWE by promoting equal opportunities, epilepsy awareness, and developmental services. They offer counselling, support groups, protective workshops and income generation projects to PWE. Epilepsy SA offers support and employment opportunities to anyone with epilepsy. Epilepsy SA is a huge strength within the epilepsy community as it strives for equal opportunities for PWE, as well as offering various resources to aid PWE to live with, and adjust to, their condition. The protective workshops are comprised primarily of individuals living in impoverished areas.

The participants for the pilot study were purposefully sampled through Epilepsy SA. The motive for using purposeful sampling will be discussed in section 3.4.1. The senior social worker at Epilepsy SA approached appropriate candidates working in the protective workshops and asked if they were willing to take part in this study. Initially, 10 participants were purposefully selected. However, there were significant language barriers with three of the participants and there were no available translators. Therefore,

the final sample consisted of seven participants. The inclusion criteria for participants were 1) that they had a diagnosis of epilepsy as confirmed by a clinician, 2) were 18 or older, and 3) were able to speak English.

3.3.2 Data Collection

Data was gathered via semi-structured interviews lasting approximately 40 minutes. All the data collection methods of the pilot study were comparable to the data collection methods of the data collection for this Master's dissertation. Please see section 3.4.2 (Data Collection) for details.

3.3.3 Measuring Instrument

A number of questions were developed to structure the interviews. The questions were developed through information found in a literature review and other questions were added that were relevant to the study's research question. The questionnaire comprised of 44 items in 6 sections: Participants' demographics, needs, management of epilepsy, understanding of epilepsy, plus items relating to their "felt" stigma and items relating to enacted stigma were covered. All questions were open-ended.

3.3.4 Data Analysis

Data was analysed via thematic analysis, following the principles that Braun and Clarke (2006) outlined in their paper, *Using thematic analysis in Psychology*. Please see section 3.6 (Data Analysis) for more detail about this method.

3.3.5 Outcomes of Pilot Study

In my Honours research project, all seven participants reported on significant challenges they faced with living with epilepsy, and themes of "felt" and enacted stigma came through in the interviews. This will be discussed in Chapter 4 in more detail. I found that participants were willing and open to talk in person about living with epilepsy, and that one-on-one interviews were able to draw out in-depth detailed information from participants about their experiences and perceptions. However, interview time was restricted in these interviews to approximately 40 minutes, and extra time would have been more beneficial to allow participants to engage more fully with each question. In

addition, as participants were only recruited from a protective workshop, many experienced the same environmental struggles of living in poverty. A broader representation of participants would have been preferable and more in keeping with an ethnographic approach (Murchison, 2010). Lastly, some participants had mild cognitive impairments which also brought additional complexity and challenges to the interviews. Based on the experience of the pilot study, I shortened the questionnaire for the Master's research component, and based questions more closely on existing standardised scales that measured epilepsy-associated stigma and arranged for extended time with participants. In addition, I purposefully sampled a broader range of participants from more diverse backgrounds. The rich and interesting findings from my Honours project encouraged me to continue this research as a Master's dissertation.

3.4 The Case Studies

The case studies presented in Chapter 5 of this dissertation will be written from a first-person perspective. As previously discussed, in an attempt to reduce my subjective influence over the interpretation of the data, I will endeavour to present large portions of raw, transcribed data and write the case studies in the first person. Writing from a first person perspective allows a form of transparency about how the author may influence the research process and data analysis (Braun & Clarke, 2006). The third person perspective tends to ignore the social factors that are at play in a qualitative research process (Webb, 1992). Foster and Parker (1995) suggest that writing from a first person perspective is a way to acknowledge the active and subjective role of the data analyst (Foster & Parker, 1995). By using this method, the aim is to not to impose my voice as superior over that of the participant. It is socially and scientifically responsible to acknowledge both my influence on the research process (as both interviewer and analyst), and to minimise any bias in the interpretation of what was said, as is encouraged in the literature (LeCompte & Schensul, 2010).

3.4.1 Population and Sampling

Three participants will be purposefully sampled through the Head of Epilepsy

South Africa. Purposeful sampling is a frequently used technique in qualitative methods and was chosen as it is the most appropriate method to identify participants who can impart in-depth personal knowledge that will answer the research question. Purposeful sampling will enable the identification of participants who are willing, information-rich resources who have the ability to articulate their experiences in a detailed and reflective manner (Palinkas et al., 2015).

The Head of Epilepsy South Africa will approach PWE well known to the organisation and to herself. She will approach these individuals, asking if they would be interested in taking part in this study, and ask their permission for the researcher to contact them and arrange an interview. In addition, the Head of Epilepsy South Africa has agreed to also contact a neurology specialist at a tertiary-level public academic hospital in the Southern Suburbs of Cape Town, South Africa. The hospital sees approximately 500 000 out-patients and 50 000 in-patient admissions a year. The neurologist will be asked to find patients who meet the inclusion and exclusion criteria to participate in this research from the pool of patients who attend regular appointments at the outpatient Epilepsy Clinic at the hospital. The neurologist will approach suitable patients, asking if they would be interested in taking part in this study, and asking their permission to be contacted for an interview.

The participants will be selected based on the following criteria:

Inclusion criteria:

- A diagnosis of epilepsy as confirmed by a neurologist
- Is able to verbally communicate in English
- Cognitively competent to participate
- 18 or older

Exclusion criteria:

- Does not have a diagnosis of epilepsy
- Has been seizure free for many years
- Cannot verbally communicate in English

- Severe cognitive impairment
- Less than 18 years of age

3.4.2 Data Collection

For this study I will gather data via semi-structured interviews lasting approximately 90 to 120 minutes. The interview will be partially structured using adapted questions from a range of standardised scales designed for investigating epilepsy stigma.

The choice of using interviews as a data collection method was chosen as it is the most appropriate method to obtain data to answer the research question. Interviews are appropriate methods to capture in-depth detailed personal experiences. The decision to use a semi-structured interview to obtain data is due to the following: firstly, partially structuring the interview, allows the researcher to stay on the topic, secondly, it sets an appropriate flow of questions, and thirdly, it allows the researcher the opportunity to follow the participant's lead, thereby providing an opportunity to identify new ways of seeing and understanding the topic and getting a much more accurate and personalised understanding of the participant's perceptions and experiences. Lastly, due to the sensitive nature of the topic, interviews will be conducted one-on-one. This is to give the participant anonymity and confidentiality and thus allowing them privacy to be more open with information (Cohen & Crabtree, 2006).

The participants' interviews will be recorded. The interviews will be voice-recorded and later transcribed. The decision to voice-record as opposed to having a scribe present is twofold: first, because there is no financial budget to hire a scribe for the interview, and secondly, due to the sensitive nature of the topic being discussed, one-on-one is more desirable. Were the interviewer to scribe during the interview, the interview would become disjointed and it would be difficult to build rapport. The interviews will be voice-recorded using a recording function on my cell phone. A cell phone offers two advantages over a dedicated voice-recording machine, as it is readily available and is less intrusive as it is a normal everyday item for most people. The participants will be asked to sign a consent form, confirming their willingness to participate

and to be recorded before the interview takes place. Further details are discussed under section 3.5 (Ethical Considerations).

During the interviews, in an attempt to minimise my subjective interpretation of participants' responses, I will implement a reflective listening technique.

Reflective listening is a person-centred therapy technique developed by Carl Rogers, where the interviewer's aim is to understand and confirm speakers' ideas by paraphrasing what was said back to them in an attempt to see that it has been understood correctly (Arnold, 2014).

3.4.3 The Interview Questions

Self-constructed questions were developed for the interview. These questions were developed by experience from the pilot study, and from consulting a range of standardised scales for investigating epilepsy stigma. Items from these scales were adapted to be open-ended questions for the interview setting to elicit stories and lengthy explanations. The questionnaire comprised 18 items. These questions aimed to explore the lived experienced of having epilepsy and the associated stigma. Table 3.1. shows a list of scales which were consulted to draw up the interview questions.

Table 3.1

Standardised scales used to construct interview questions

Scale Name	Author	Description
Mastery/Locus of Control Scale	(Pearlin & Schooler, 1978)	Measures degree of internal vs. external locus of control.
Stigma of Epilepsy Scale	(Jacoby, 1994)	Patients' perceived level of stigma associated with epilepsy.
Seizure Worry Scale	(Jacoby, 1994)	Measures the extent of seizure related worry.
Stigma Scale of Epilepsy	(Fernandes, Salgado, Noronha,	Measures "felt" stigma among people with epilepsy.

	Sander, & Li, 2007)	
Awareness Scale	(Fisher et al., 2000)	Measures a person with epilepsy's perceptions about stigma, education, and awareness around epilepsy.
Number of Seizures Scale	(Jacoby, 1992; Jacoby, Baker, Steen, Potts, & Chadwick, 1996)	Assesses the frequency of seizures in the past 12 months.
Work Limitations Scale	Adapted from Martin, Meltzer & Elliot (1988) and Ware (1993)	Measures a person with epilepsy's perception of epilepsy-related social limitations.
Social Limitations	(Jacoby, 1992)	Measures a person with epilepsy's perception of epilepsy-related work limitations.
Social Support	(Jacoby, 1992; Jacoby et al., 1996)	Measures who provides support to the person with epilepsy and whether the person providing support has changed his/her behaviour toward the person with epilepsy.
Self-concept	(Jacoby, 1992; Jacoby et al., 1996)	Measures the extent to which epilepsy impacts on a person with epilepsy's self-esteem.
Ambition Limitations	(Jacoby, 1992; Jacoby et al., 1996)	Measures a person with epilepsy's perception of epilepsy-related ambition limitations.

Kilifi Stigma Scale for Epilepsy	(Mbuba, Abubakar, Odermatt, Newton, & Carter, 2012)	Measures perceived stigma among people with epilepsy
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The scales listed in Table 3.1 are standardised tools which have been validated and used extensively in epilepsy stigma research. Most are subscales in the Quality of Life in Newly Diagnosed Epilepsy Battery (NEWQOL) – a self-administered 93-item battery designed to assess quality of life in people with new-onset epilepsy (Abetz, Jacoby, Baker & McNulty, 2000). However, they have been mostly developed and validated in Western and middle-income countries. Therefore, tools which have been validated in low-income countries, namely the “Kilifi Stigma Scale” and the “Epilepsy Stigma Scale” have also been included to capture a difference in cultural perception of stigma within the South African context. To date, no scales have been validated in the South African context (Fernandes, Salgado, Noronha, Sander, et al., 2007; Mbuba et al., 2012).

3.5 Ethical Considerations

Ethics approval has been granted by the Ethics Committee of the Unisa Department of Psychology.

3.5.1 Informed Consent Procedure

The participants will be given a printed consent form in their preferred language (see Appendix A). They will also be verbally guided through the consent form, and clearly informed that the interview would be voice-recorded, and their consent will be required. After the study and consent procedure will be explained, the participants will be asked if they have any questions or concerns. The participants will be informed that their participation is voluntary, and that they are free to leave the interview at any stage, if they no longer wish to continue. Lastly, they will be then asked to sign the consent form, acknowledging their consent. Furthermore, no incentives will be offered to the participant for taking part in this study. As participants will be over the age of 18 and cognitively competent, consent will only be required from the participant and no guardian is required to give consent on their behalf. There

are no foreseen risks or costs to the participants taking part in this study. The participants' identity and information will remain confidential and anonymous.

Should information be revealed in the interviews that indicates that the participant may wish to harm themselves, or require further attention from clinicians, the Head of Epilepsy South Africa will be contacted. In the event that the interview brings up any uncertainty for the patient, the Head of Epilepsy South Africa will request the neurologist who recruited the patient to send a follow-up appointment to the patient for closure of the interview process.

3.6 Data Analysis

Many experts (Bradley, Curry, & Devers, 2007) have argued that there cannot and should not be a uniform approach to qualitative data analysis methods. There is in fact a disagreement in the literature between researchers on best coding practices (Willig, 2003). However, what is certain, is that methods used should be appropriate, explained and justified in the methodology (Anderson, 2010). For the purposes of this study, data will be analysed via thematic analysis, following the principles that Braun and Clarke (2006) outlined in their paper, *Using thematic analysis in Psychology*. Thematic analysis codes the data into meaningful categories and aims to identify broader themes in the data, which answer the research question.

Following the 6-step guide by Braun and Clarke (2006), I will complete the following steps:

1. Become well acquainted with the data by listening to the recorded interviews and transcribing the interviews.
2. Create an initial list of ideas of interesting content from the interviews, generate codes for the itemised content and start to compress this data into defined categories.
3. All relevant data will be coded, sorted, and collated into broader themes.
4. Consider the broader themes that have emerged which answer the research question.

5. Further define and refine themes in the data in relation to answering the research question.
6. Once a full set of worked up themes and categories has been acquired that are relevant to the research question, the write up will start.

This method was chosen as it closely aligns with the ethnographic approach, which is to identify key themes which emerge from the data. Key themes are anecdotes that repetitively emerge from the data; repeated stories, phrases, feelings, perceptions or ideas (Murchison, 2010). Lastly, in the write-up of the data, in an attempt to reduce my subjective influence over the interpretation of the data, I will endeavour to present large portions of raw transcribed data.

3.7 Limitations and Scope of the Study

A limitation of this study is that only one in-depth interview per participant was feasible. If follow-up interviews, and interviews with individuals close to the participants had been possible, this would have created a much richer expanse of knowledge.

Critics will claim the limitations of a qualitative ethnographic research approach is the influence the researcher has on the research process, both in their interaction with the participant and in the more subjective approach in interpreting the data. Mitigating steps will be taken to counter-act the interactive role the researcher plays in an ethnographic research approach. First, a reflective listening technique will be employed in the interview process. Second, large portions of raw transcribed data will be presented in the write-up and, finally, to ensure transparency, findings will be written in first-person.

The sample size of this study is small. The pilot study consisted of seven participants and the main study consists of three participants. This is a qualitative study that aims to explore the impact of having epilepsy on an unrepresentative number of individuals. Therefore no generalisations are made to a larger group. The observations from this research cannot be extrapolated from these single personal experiences to be applicable throughout South Africa. Rather, the scope of this paper is to explore these

individuals' lived-experience of having epilepsy and the associated stigma in their context.

3.8 Conclusions

The aim of this study is to explore the lived experience of living with epilepsy and the associated stigma. Participants will be purposefully identified through the Head of the Western Cape branch of Epilepsy South Africa. Using a qualitative method, following an ethnographic approach, data will be gathered via informal, semi-structured interviews. An initial pilot study (n=7) was completed which informed the research strategy for this Masters. An additional three people with epilepsy will be recruited and more in-depth interviews will be conducted. Data will be analysed via thematic analysis following principles laid out by Braun and Clarke (2006). Steps will be taken at various stages of the research process to mitigate subjective influences over data gathering, analysis and presentation. Observations from this research cannot be used to generalise to all persons with epilepsy throughout South Africa. Rather, the scope of this paper is to tell a story about these individuals' experiences of having epilepsy and the stigma they experience in the context of living in South Africa.

Chapter 4 Pilot Study

4.1 Introduction

Following qualitative methods, an initial pilot study was conducted which held 40-minute one-on-one interviews with seven people with epilepsy. The pilot study was done to investigate if epilepsy stigma is a challenge faced by PWE in South African communities and to gather background information which could be used to guide the logistics and questions of the next stage of the research as explained in Chapters 3 and Chapter 5. This chapter will discuss the findings from the interviews conducted as part of the pilot study.

4.2 Participant Demographics

Seven participants were enrolled in the pilot study. Table 4.1 below shows an overview of the demographics of the enrolled participants. Four females and three males were recruited. Their ages ranged between 23 to 59 years old (mean age: 40 years). Their level of education ranged from Grade 5 to Grade 12. Only two participants had successfully completed Grade 12. The next highest level of education was Grade 10 (mean level of education: Grade 9).

All the participants had been diagnosed with epilepsy in their childhood and all lived in low socio-economic communities. All participants' main source of income was a disability grant from the government, and some received weekly wages for working in the protective workshop of Epilepsy South Africa. None of the participants were currently married, one was divorced, and 3 were in long-term committed relationships (mean relationship period: 5 years). Only one of the participants' partners had also been diagnosed with epilepsy.

Table 4.1

Pilot Study Participant Demographics

Participant	Age	Gender	Highest level of Education	Income Source	Marital Status	Dependents	First Seizure (age)	Frequency of Seizures
#1	42	M	Gr 7	D.Grant	Single	Yes ^{*1}	7yrs old (HT)	1 x month
#2	51	F	X	D.Grant	Single	Yes ^{*2}	+18yrs old	2 - 3 x month
#3	34	M	Gr 10	D.Grant & EpiSA wages	Single	No	12yrs old	1 x every two months
#4	23	F	Gr 12	X	Single	No ^{*4}	12yrs old (HT)	Last seizure was two years ago
#5	27	F	Gr 12	D.Grant	Single	No	5yrs old	Last seizure was a few months ago
#6	59	F	Gr 10	D.Grant & EpiSA wages	Divorced	Yes ^{*6a}	14yrs old	N/A ^{*6b}
#7	44	M	Gr 5	D.Grant & EpiSA wages	Single	No	11yrs old	X

X – No information was retrieved from participant.

HT – Head Trauma.

EpiSA wages – Wages received from working at the protective workshop at NGO Epilepsy South Africa.

D.Grant – Disability grant from South African government.

*1 – Has no relationship with child, child lives with birth mother.

*2 – Child was taken away as she couldn't look after the child due to bad seizures, which could potentially harm the child.

*4 – Was pregnant but lost the child during a bad seizure.

*6a – Had two children, but they died at 21 and 17 years, due to muscular dystrophy.

*6b – Participant lives alone and has seizures at night (when asleep) and therefore is not aware of when they are happening.

PWE tend to have lower levels of education, and are less likely to be married and more likely to be unemployed (Ahmad, 2011; Baker et al., 1997).

However, these findings should be viewed in the context of the socio-economic environment these individuals live in and the historical background of South Africa. In regard to the findings about education – according to data released by Statistics South Africa of the residents of the City of Cape Town, 5,3% of people aged 20 years and older have only completed Grade 5 or less; 50,2% have not completed Grade 12; 29% have completed Grade 12 and 18,8% have completed studies past Grade 12 (Statistics SA, n.d.). Also, in the specific communities from which the participants were recruited, there is a school dropout rate of 43.1% (Western Cape Provincial Treasury, 2012).

Therefore, a correlation cannot be drawn that these participants have lower levels of education or are unemployed as a direct result of their epilepsy. It could equally be a result of their socio-economic environment and historical circumstances. In contrast, two participants (#4 and #5) successfully completed Grade 12. This would place them both in the upper (or third) quartile regarding their level of education within their communities. Participant #4 reported having infrequent seizures. Evidence shows a linear relationship between severity and stigma (Baker et al., 2001; Jacoby, 1992, 1994; Jacoby et al., 2001) which could be the reason for her higher educational achievement. Participant #5 only had her first seizure after finishing Grade 12, therefore, her epilepsy would not have been a factor in her level of education.

Lastly, the historical background of South Africa could also be an influencing factor in the participants' level of education in these communities. All participants in the pilot study are persons of colour. Participants who were children in the 1970s and 1980s would have been enrolled in South Africa's apartheid schooling system for the duration of their school career. The apartheid regime's "Bantu" education policy enforced differing educational opportunities between ethnic groups, where people of colour were disadvantaged. The apartheid government spent significantly less on the education of people of colour and the quality of teaching was poor. In addition, people of colour were often taught in their second or third language rather than their mother-tongue. The effects of the educational inequality between

ethnic groups in the “Bantu” education system of the apartheid regime, are still felt today, post-1994 (Boddy-Evans, 2017).

In summary, a further investigation into the reasons for a participant not completing their education, would be needed to distinguish between the role played by epilepsy and the role played by historical social disadvantage.

4.3 Health Education

4.3.1 Superstition

In this study, none of the participants reported superstitious beliefs, either personally or in their communities.

As Mushi et al. (2011) point out, the differences in knowledge about epilepsy could be related to the access to information in the community. More rural and remote communities, which rely solely on the medical guidance of traditional healers, will have had their understanding shaped by these traditional indigenous beliefs. However, the participants enrolled in this study live in an urban area, with access to a choice of modern medical facilities. Therefore, the participants have access to health practitioners to inform their understanding. In addition, the participants were recruited through Epilepsy South Africa, which does a lot of community work in raising awareness and education about epilepsy. This could explain why the participants a) did not hold superstitious beliefs and b) had not encountered others who held superstitious beliefs.

4.3.2 Level of Understanding

Although the participants did not hold superstitious beliefs about epilepsy, they did express sometimes seemingly overly simplistic understandings of epilepsy and also held incorrect⁷ beliefs and interpretations about what may trigger a seizure. The participants indicated that if one were to get “excited”,

⁷ Currently, there is no scientific evidence that reliably indicates that there is a direct relationship between stress and seizures. However, there are studies being conducted to investigate this relationship. The current opinion is that in some cases seizures are caused through combinations and interactions of several variables. Stress may be one of many variables, which interact and contribute to triggering a seizure (Privitera, Haut, Shafer & Sirven, 2013).

“upset”, “depressed” or “nervous” then they would “get sick” (have a seizure). There was also mention of “sunlight”, “heat”, “pressure” and “stress” as being triggers for a seizure. Responses include:

"because they say if you get upset with someone and excited then you will get sick and they say also sitting in the sun, it will also get you sick. Sunlight will and drinking alcohol with your medication, that will also, it will make you get sick" (Participant #1).

"say you have an argument with your own family and then you upset yourself and then you will most obviously get a fit. If you have got a dislike in someone and you don't want to talk to that one at all but she always in your eyesight or so and then you don't know what to do . . . now you upset yourself over that one and then you get your fit too . . . or if you got a hatred in your life" (Participant #2).

"well they actually told me what happens if I got too much pressure, especially at home or here at work, I get a seizure, that's what they told me When you have too much pressure on you, you get a seizure, or something like that" (Participant #3).

"I must just not get stressful, or depressed . . . if I have a party I must not drink, or get too excited, or depressed I still want to study more, but when I study, I just get the seizures so much, I don't know why, maybe I get depressed or it's because of the lot of work I have to do or something" (Participant #5).

"doctors always say it's my nerves, I am very nervous, that is what the problem is, I don't know what happened in my life when I was a child, but I think my father was always fighting with my mother" (Participant #6).

In a study by Shorvon and Farmer (1988) they found that beliefs in developing countries about causation were more heavily focused around spiritual, environmental and psychological causes (Shorvon & Farmer, 1988). They

identified “worry”, “guilt”, “anger”, “craving” and “broodiness” as misbeliefs of psychological causation for epilepsy.

Some participants in this study did appear to have a correct, albeit simplistic, understanding about the causation of epilepsy. Some explained that they had suffered a head trauma as a child and that is why they have epilepsy.

Participant #5 said, *“I have a drop of blood here in my brain so that’s why I have seizures”* and Participant #4 said, *“messages don’t go through exactly the way they should”*. However, participants widely held misbeliefs about the triggers of seizures. All the participants reported being told this information. The findings of Allotey and Reidpath (2007) revealed that participants in their study were erroneously informed by medical and nursing staff “to take things easy” as well as avoiding sunlight, vigorous exercise and sexual intercourse. Participants in this study may be misinformed about the triggers of seizures due to a) community misbeliefs which informal home carers adopt, b) knowledge gaps of lower level healthcare workers who then pass on misinformation and c) patients misinterpreting and not understanding the information health practitioners provide. A belief that “sunlight” or feelings of “excitement” and “being upset” evoke seizures may lead PWE to make decisions not to take part in various activities. This lack of understanding of their condition may cause participants to withdraw from social activities.

4.4 Word usage

The participants used a variety of terms and phrases to refer to epilepsy and having seizures, despite the interviewer consistently only using the terms “epilepsy” and “seizures”. The participants frequently referred to *“getting sick”* or having a *“sickness”*. However, some participants did also use the terms *“epilepsy”*, *“epileptic”*, *“attacks”*, *“fits”* and *“seizures”*, but very rarely. All the participants made reference to *“getting sick”* or having a *“sickness”*, however, occasionally a few participants used the medical terms and then these terms would be used interchangeably throughout the interview.

A study by McQueen and Swartz (1995) in a rural community in the Western Cape, South Africa, also found that participants used variations of the terms

“sick” and “sickness” to refer to their epilepsy and seizures. They proposed this use of language was a mechanism to dissociate from the stigmatised label of being identified as an “epileptic”. By using the normative terms “sick” and “sickness” they align themselves with a more “normative” self. Other researchers (Allotey & Reidpath, 2007; Scambler, 2011) argue that this use of language embodies how a person with epilepsy fulfils the “sick role” and identifies themselves as a “sick person”. In section 4.6.1 (Self-concept) a more detailed analysis of the embodiment of the sick role is given.

Although these are interesting propositions and should be considered, one cannot ignore the level of education and mother-tongue language of the participants enrolled in the studies. The choice of language could relate to a limited vocabulary, as a result of low levels of education, in addition to English likely not being their first language. The terms “epilepsy” and “seizure” are medical terms and therefore it may be more appropriate for them to use everyday terms that are more comprehensible and relatable to others. This point is supported by one of this study’s participants using the term “*sugar sickness*” to refer to a friend who had diabetes. A South African study which reported on local terminology for diabetes showed that in Northern Sotho speaking communities, traditional healers identified the local term for diabetes as “*Bolwetsi bja swikiri*”. The literal translation of this is “disease of sugar” (Peltzer et al., 2001). There is a wide spread of languages (11 official languages) in South Africa, and many speak English in addition to their mother-tongue, as this is the language of business, media and politics (Posel & Zeller, 2016). It is therefore conceivable that clinical terminology may morph into different, perhaps more comprehensible, conversational terms with back and forward translations between the local languages.

4.5 Enacted Stigma

In this study some participants reported instances where people would treat them differently as a direct result of their diagnosis. Some participants reported that people felt uncomfortable around them, and therefore would avoid them. The main reasons participants reported why they thought people were avoiding them was because the person did not know how to handle

them if they were to have a seizure, and therefore would rather avoid the situation. This aligns with the findings of another study done in the UK (Robson, 2006). Responses included:

"ja . . . they were scared to even be with me at the same time, even for an hour or so, they would just make it so obvious . . . they would say like I need to be home, I need to get home . . . that's why I've never had friends, I still don't . . . Other kids were nervous because they didn't know how to help me if I should have a seizure" (Participant #4).

"sometimes people judge you, some people stay away" (Participant #5).

A participant also reported that people felt sorry for her, and her family:

"some people treat me differently, it's like they feel sorry for me, some, where I stay, say to my family, I am so sorry for you, your child is epileptic, [PWE] can't do things like go to parties" (Participant #5).

Another participant reported that, as a child, his brothers, children at school and a neighbour would tease him about having epilepsy:

"my brothers used to tease me . . . call me names . . . children at school did to . . . also, the neighbour . . . I hardly have friends . . . because of my sickness" (Participant #1).

Austin, Shafer and Deering (2002) reported that 63% of 20 000 American high schools students that they interviewed, believed that PWE were more likely to be bullied than other youths. In the context of Goffman's (1963) beliefs, this participant was "discredited" by his peers due to his "undesired differentness" therefore making him a valid target (in their eyes) for bullying.

It is likely that these instances of enacted stigma can make a person with epilepsy feel rejected by society. In addition, studies show that stigma-related stress further contributes negatively to a person's wellbeing (Cree et al., 2006; Flowers et al., 2006; Mays & Cochran, 2001). These overt discriminating gestures or behaviours toward a person with epilepsy can make them feel

inferior and upset. Link and colleagues (1989) suggest that through socialisation in this negative environment, PWE adopt these negative beliefs of themselves. In fear of being judged, they turn to secrecy and withdraw (Link et al., 1989). Operant conditioning⁸ theories would also offer a plausible explanation as to why PWE would begin to avoid circumstances where these undesired situations could arise.

4.6 Perceived or “Felt” Stigma

Scambler and colleagues’ “hidden distress” model, described in detail in Chapter 2, (Scambler, 1989; Scambler & Hopkins, 1990) was recently revisited (Scambler, 2011) and remains in his opinion a credible explanation of epilepsy “felt” stigma. However, not every person with epilepsy fits into the “hidden distress” model. Jacoby and colleagues’ studies (Baker et al., 2001; Jacoby, 1992, 1994; Jacoby et al., 2001) revealed a linear relationship between epilepsy severity and “felt” stigma and others have said this linear relationship is influenced by interacting factors like perception of limitations, education (Ryan et al., 1980), professional and informal support (Suurmeijer et al., 2001) and side-effects of medication (Baker et al., 1997). These confounding factors may explain why some PWE who have well-controlled seizures still experience “felt” stigma. The following sub-sections below delve deeper into the facets of what comprises “felt” stigma.

4.6.1 Self-concept

“Felt” stigma may shape the self-concept of a person with epilepsy. As Scambler’s “hidden distress” model conveys, a person with epilepsy fears discrimination and perceives themselves to be “socially undesirable”, embodying a “sick person” identity (Scambler, 1984; Scambler, 1989; Scambler, 2004, 2011; Scambler & Hopkins, 1986, 1990).

In this study, some participants reported that they were cognitively “slow”. Participant #2, while explaining a story about a bad seizure she experienced,

⁸ Operant conditioning is a behavioural learning theory developed by B.F. Skinner. It is a form of learning in which voluntary responses become controlled by their consequences (Weiten, 2007).

equated herself to a “*Valkenberg*⁹ woman” and referred to herself as being “*unhealthy*” and also claimed “*you must excuse me, I’m not so good in thinking*”. Furthermore, the overwhelming majority of participants showed a clear lack of confidence in their ability to answer the interview questions, and some participants would seek feedback and query if they were answering the questions correctly.

This use of language and lack of confidence in their abilities could suggest an internalising of the “sick role”. As explored under section 4.5 (Enacted Stigma), Link and colleagues found in their study, some PWE were found to internalise the “sick role”, and identified themselves as “disabled”, “chronically ill” and “always unwell” (Allotey & Reidpath, 2007). It could be a result of a self-fulfilling label that society has projected onto them through the socialisation of the stigmatising nature of epilepsy (Link et al., 1989). Furthermore, it is recognised that anti-epileptic drugs (AED) can cause deficits in memory and mental slowing (Baker et al., 2001). Also, if their epilepsy was a result of a head trauma, it is conceivable that other areas of the brain may have suffered trauma, which could have led to cognitive impairments. Therefore, it is plausible that they may be cognitively impaired for a known medical reason. Regardless, their choice of words still illustrates a negative self-concept that has formed and highlights an internalisation of a “sick role”. A person with a negative self-concept is likely to have self-esteem, self-confidence and self-worth issues (Weiten, 2007).

4.6.2 Being “Normal”

Some participants reported on their desire to be perceived as “normal” and actions they took to try to achieve this “normal” status,

Participant #3 explained that he knew how to drive a car, but due to the severity of his epilepsy he is not allowed to drive as per South African law. It is difficult to feel “normal” when you are restricted from performing daily tasks

⁹ *Valkenberg is an inpatient psychiatric hospital in Cape Town, South Africa.*

that the rest of society (e.g. driving a car) engage in. Even though he knows how to drive a car, he says it's a secret. He says he does not tell his friends that he knows how to drive. This is his way of normalising himself, as people will think he doesn't have a car because he doesn't know how to drive, as opposed to, he doesn't drive because he has a neurological disease which legally prevents him from driving.

Participant #4 explained how she did not always keep to the schedule of her AEDs as she does not like the feeling that she “depends” on medication. Aside from the adverse side-effects of AEDs, being on chronic medication can be difficult. The routine of taking daily medication can make a person feel “different” to others:

"because I don't want to depend on medication. I know it doesn't cure, but it helps. Like every week I take it, like maybe Monday, Wednesday, Friday and weekends I take it, but I don't want to depend myself on medication. If I'm like this, I know I can, I know I have it, but I don't want to depend on it. I want to be just told that I am cured, I am not getting seizures anymore Sometimes I just miss a few to try it out. I don't want to depend on tablets every time when I go here and there" (Participant #4).

4.6.3 Social Support

Social support can play a fundamental role in helping a person with epilepsy adjust to life with having epilepsy. However, misinformed or overprotective carers can reinforce the “sick” identity. Literature shows that PWE tend to adopt a “sick role” and adopt a new identity by identifying as being an “epileptic” (Link, 1987; Link et al., 1989; Scambler, 1984; Scambler, 1989; Scambler & Hopkins, 1986, 1990). Participant #2 explained how she went through a “childish life”. She was raised by her aunt from a young age, and her aunt always treated her like a child as a result of having epilepsy:

"my aunt treated me like a child, she always handled me as a child, didn't let me work with adults and that, I had to go through a childish life" (Participant #2).

Participant #4 explained how her parents were overprotective, and restricted her from doing certain activities, such as sleepovers with friends:

"[My parents] were overprotective, obviously, because I couldn't sleep-over and I couldn't do this, because they expected I'd have a seizure at any time" (Participant #4).

Informal carers who are overprotective and treat the person with epilepsy as not capable of looking after themselves, tend to reinforce the "sick role". They become "stigma coaches" (Schneider & Conrad, 1980) who impose their perceptions onto the person with epilepsy, who then in turn internalise these feelings. This is a common dynamic, often set up between parent and child, whereby the parent tends to overprotect the child (Schneider & Conrad, 1981; Williams et al., 2003). Overprotective parents will place restrictions on the child with epilepsy. For example, in Participants #4's situation, the parent does not allow her to sleepover at other people's houses. These restrictions in childhood feed into adulthood and the person with epilepsy continues to limit herself as result of being conditioned (Jacoby & Austin, 2007). The consequences of "stigma coaches" is seen in a study by Collins (1990) where the adult participants describe feeling less valuable, less adaptable, less dependable, less mature, less stable, less able to cope, less successful and less well-adjusted than the general population (Collins et al., 1990).

4.6.4 Fear of the Next Seizure

All participants reported that the embarrassment a person with epilepsy feels from having a seizure, the fear of not knowing when the next seizure is going to happen and the fear for their safety when having a seizure are the hardest aspects of this condition to cope with. Responses regarding fear of safety included:

"it's a huge thing for [PWE] because they might get robbed along the way or so or just they get a seizure in the road or so then people walk past and say oh this guy is drunk or so or whatever and take his wallet or his phone or anything like that" (Participant #1).

"sometimes I can't really enjoy myself, because I am thinking of it [People who have frequent seizures] must be scared to travel alone, or to bath alone, because they don't know when it will happen, but I think that's the challenge, when like they don't trust themselves" (Participant #4).

"I think [PWE] should not stay alone, there should always be someone with them, because anything can happen, because lots of things have happened with me while I was alone Before I was busy with sports, the seizures are why I don't do it anymore, because I was afraid I get a seizure while I am busy with it" (Participant #6).

Participant #2 explained how she doesn't want to be reminded of having a seizure. She would prefer that people politely avoid conversations about any seizures she may have had in public. Presumably, having a seizure may be embarrassing and she fears people who witness her having a seizure will then perceive her as "different":

"if I get a fit today and now I come tomorrow to you don't talk every time of that way I had that fit because that's something you mustn't remind one of, also, it was told to me, if you get today a fit and a person went on or maybe did something wrong in this place, don't remind them to tomorrow, she did this or that, she was acting like a funny person or so, don't remind her of that because that's just what happens today and what happens today is the past" (Participant #2).

The fear of when the next seizure might occur is worrisome for a person with epilepsy. They are worried that other people may see them having a seizure, or that something bad will happen to them during their seizure. People with epilepsy are likely to avoid situations that would result in them being either hurt or embarrassed if a seizure was to occur. In this way, PWE often isolate themselves and withdraw. The fear of embarrassment resides in the "felt" stigma PWE experience. As Scambler suggested, PWE fear they will be judged and discriminated should the public find out they have epilepsy. They fear they will be "discredited" and become "socially undesirable" (Scambler,

1989; Scambler & Hopkins, 1990). This act of concealment becomes very disruptive to their lives, as they live in continual fear of experiencing enacted stigma.

4.6.5 Disclosure

In this study participants appeared divided on the matter of disclosure for varying personal reasons. This response may be very telling of the severity or nature of the personal “felt” stigma a person with epilepsy experiences. The participants who said they did conceal their epilepsy from others gave responses such as:

“sometimes people judge you, some people stay away” (Participant #5).

“I thought to myself it is not necessary to tell everybody about your fit . . . similar to a secret you can keep in mind” (Participant #2).

The above responses are indicative of the repercussions of “felt” stigma. People with epilepsy worry they will be judged by others and therefore try and keep their diagnosis a secret to protect themselves from potential discrimination and judgment. Other studies both in South Africa (Keikelame & Swartz, 2013a, 2013b; McQueen & Swartz, 1995) and abroad (Mugumbate & Mushonga, 2013; Mushi et al., 2011) highlight that many people living with epilepsy chose to conceal their diagnosis for a variety of reasons.

On the other hand, participants who chose to disclose their epilepsy seemingly did it in a desire to a) protect themselves from physical harm and b) be seen as “normal” by others. They gave responses such as:

“yes, I do tell people because then they will know what to do if I have a seizure. Friends look after me, help share the information about. They say this is [name] he has epilepsy, but he is okay” (Participant #3).

“I want people to know about epilepsy and know what to do if they see someone having a seizure. I want people to speak out, I don’t want to

feel different, like you are normal, and I am not. It makes you unique, who you are, doesn't matter what you have, it's you" (Participant #4).

"I am open about telling people about my epilepsy because I want other people to know what my problem is, if something happens then they know about it" (Participant #6).

Participants who said they were confident to disclose that they have epilepsy, said it was because they wanted people to know how to help them during a seizure and for people to understand more about epilepsy and therefore not treat them differently. As these participants are all members of Epilepsy South Africa, a NGO which sets out to educate and support people with epilepsy by providing part-time jobs and medical support, it is likely that being part of this organisation has started to positively influence these participants and allowed them to become much more socially comfortable with their diagnosis of epilepsy. Studies have shown that community interventions have had the ability to successfully change the public's and people with epilepsy's attitudes towards epilepsy (Funderburk et al., 2007; Jilek-Aall et al., 1997).

4.7 Psychosocial Impact

All participants reported that epilepsy in some way had negatively affected their relationships or desire to involve themselves in social activities.

4.7.1 Social Activities and Intimate Relationships

Some participants indicated that they feel they do not have friends as people are nervous to be around them in case they have a seizure:

"sometimes people judge you, some people stay away" (Participant #5).

"ja . . . they were scared to even be with me at the same time, even for an hour or so, they would just make it so obvious . . . they would say like I need to be home, I need to get home . . . that's why I've never had friends, I still don't . . . Other kids were nervous because they didn't know how to help me if I should have a seizure" (Participant #4).

This aligns with the findings of other studies, where PWE reported experiencing loneliness, shame, and fear of rejection (Hermann et al., 1990; Mushi et al., 2011).

The participants of this study also reported that they felt limited by their epilepsy. One of the participants mentioned how he choose to no longer spend time with his brothers and the mother of his child, as they would “party” too much, and he was nervous that this type of environment would trigger a seizure. Another participant felt similarly, and says that she does not go to parties with her friends in case she may have a seizure:

"what challenges me is like some things you can't do because you are epileptic" (Participant #5).

"before I was busy with sports, the seizures are why I don't do it anymore, because I was afraid I get a seizure while I am busy with it" (Participant #6).

Social activities of PWE are reported in the literature as being negatively impacted (Ahmad, 2011). This study reveals this is largely due to the fear of having a seizure.

As discussed earlier in this chapter, some participants had erroneous understandings of their limits. Their misunderstandings of what triggers a seizure lead them to restrict themselves quite significantly in some cases. Participant #1 believed that he should not sit in the sun, as it may trigger a seizure.

4.7.2 Education and Employment

As was discussed earlier in this chapter, the findings in this study do not necessarily indicate that the level of these participants' education is correlated with their diagnosis and severity of epilepsy. There are many other socioeconomic and historic factors at play. However, some participants do report that having seizures did inhibit them from continuing their education.

Participant #5 explained that she had always wanted to be an accountant, she had been awarded funding to enrol in a learnership program for people with disabilities, at a well-known financial services company, but the frequency of her seizures stopped her from attending and completing her studies:

“I still want to study more, but when I study, I just get the seizures so much” (Participant #5).

Also, Participant #4 reported that she would arrive late at school, as a lack of sleep could trigger a seizure:

“When I was at school [my parents] never woke me up, I had to wake up myself because I and [my parents] were too scared. If they wake me up now, maybe something will happen, and I won’t go to school. So, I would go to school at 9am sometime 10am” (Participant #4).

Although this did not stop Participant #4 from completing Grade 12 and going on to receive funding to study a course in early childhood development, it sheds light on why others might fall behind in school.

4.7.3 Coping Strategies

There was little feedback from the participants on how they coped with these challenges or how they felt these challenges could be addressed. However, there appeared to be a general consensus about PWE needing good support systems to help them manage their condition, and for the public to be educated on what epilepsy is and how to help a person with epilepsy.

4.7.4 Hard Realities

In serious cases, where a person’s epilepsy is very severe, PWE are unable to lead “normal” lives. For example, Participant #2 told me how her baby was taken away from her as she was deemed unfit to care for her child as she may unintentionally harm the baby during a seizure. Her son was taken away from her when she was 18 years old as a result of her bad seizures, and was placed in the care of another family, and she says that she does not see her son and has only met him 2 times:

“They said I almost killed my son, because of my grip, and I fall on him, and squeezed him, and they struggled to pull him from me” (Participant #2).

4.8 Conclusions

The findings in this study reveal that stigma plays a major detrimental role in the participants' lives and the nature of stigma found in this pilot study shows similarities in findings to studies elsewhere. Not all PWE experience stigma; however, for those who do there is a clear negative impact on their life. This pilot study found that all the participants tended to a greater or lesser degree to have negative self-images, and that both themselves and informal carers had misinformation about the management of their epilepsy. Some participants had encountered acts of enacted stigma, and all participants feared the next seizure and where it would occur. Participants differed on why they wished to either conceal or disclose their epilepsy to others. Participants all reported the negative impact epilepsy had had on relationships of theirs, be it social, professional or intimate. All these issues negatively impacted on their normally functioning in society. Many of these issues tended to make them socially withdraw or isolate themselves.

Chapter 5

Case Studies

5.1 Introduction

This chapter is a first-person account of the in-depth interviews I conducted with PWE in Cape Town, South Africa. The pilot study, described in Chapter 4, revealed that PWE, who were from communities in Cape Town, South Africa, faced epilepsy-associated stigma, and therefore I endeavoured to continue my investigation into this area of interest. I conducted three in-depth interviews with individuals who had been diagnosed with epilepsy, and who all came from different communities and backgrounds within Cape Town, uncovering their stories about living with epilepsy. All names have been changed to protect the identity of the participants.

5.2. Case Study 1: Mary

5.2.1. Background

Mary is a 29-year-old female. She is employed full-time and works as a teacher, educating young children and focused on early childhood development. She grew up in a low-socioeconomic community, in a poor traditional fishing community in Cape Town. She began having seizures when she was very young and was only later admitted to a local children's hospital where she was diagnosed with epilepsy when she was three years old. She recalls spending most of her childhood in and out of hospital. Her epilepsy is now well-controlled and has been for the majority of her adult life.

5.2.2. Coming to Terms with Her Diagnosis

Mary remarks on how her parents were very well supported by all the medical staff at the hospital when the diagnosis of epilepsy was first made. The healthcare professionals counselled her parents and provided a lot of information and guidance on how to manage Mary's condition. When Mary was a young child, she faced multiple challenges living with epilepsy – she experienced several adverse events associated with her diagnosis of epilepsy. However, over the years, she has embarked on an arduous journey

of personal growth and explains how she has now almost “forgotten” about her epilepsy. She says:

“I used to struggle a lot with people when I was younger because they don’t understand, they treated me differently, they used to make their own assumptions about the illness because they didn’t understand it.”

“Whenever I opened my eyes I was in hospital and when I went to school, that’s when I started asking questions, I used to ask my parents, but why does that happen to me, I could remember early on I was at school, but all of a sudden I’m in bed, I’m in home, I’m not at school anymore, and then day to day they would explain to me what it’s about, how I need to take care of myself, that I need to be alert, and things I can’t do, and things I can do, it was difficult, but eventually I understood I actually started understanding the illness and what it’s about and why I do get it and how I need to take care of myself, I need to take my medication, I need to be responsible It took time, it was a long journey, basically when I was a teenager I started understanding.”

Mary recounts how after she would have a seizure, she would experience a depressive episode:

“When I was a teenager, to be honest, after a seizure I used to be depressed for about five days and then I wouldn’t go out in public. I wouldn’t go back to where it happened for a few days because emotionally it takes a lot of your energy.”

She goes on to explain how the children growing up with her in her community used to tease her:

“I was always in a special primary school, so, in my community people wouldn’t understand why I am in a special school but the reason why I was in a special school was because of the medication and my brain not functioning due to the medication and things like that so back then I was always labelled like I am in a crazy school or something or there’s something crazy wrong with me or things like that – they didn’t know it

was because of the medication I was on It was basically people in the community where I lived back then – yeah – the village was like your child is my child, my child is your child, we all live in a small fishing village and everybody knows everybody, so I basically think its uneducated people that didn't understand."

However, even with the struggles she faced, she recalls how her parents kept her positive and helped "protect" her from negative experiences:

"I was lucky I had parents who were a very good support structure My parents would always keep me on a positive journey and encourage me and send me to workshops and keep me around positive people and things like that and those things helped me a lot, it helped me understand people's mindsets That is why today I understand, and I don't blame people for what they said as I came to realize that they are not educated about it, they don't understand so you can't blame them."

Mary remarks how now she is wholly accepting of her diagnosis and she does not let it limit her in anyway:

"Throughout the years I have come to experience with this illness it depends on you, if you don't change your mindset, if you don't change the way you look at it, it's not going to be an easy road for you, because if your mindset is on the right track, whatever peoples thinks, whatever peoples says is not going to bother you because you actually understand what it's about and you know why you got it, there's a purpose and a plan for why you got this illness then whatever peoples says doesn't actually bother you."

When discussing the issue of disclosure, she explains that she is happy to talk to people who ask or who are interested, but she won't actively volunteer the information, as she feels the act of doing this means she is labelling herself:

"I won't basically say, 'I've got epilepsy'. I won't do that because I also don't want my mindset to be, 'you've got epilepsy', 'you've got

epilepsy', but if somebody asks me or if I say I can't have that or I can't sit in front of that computer any longer and then they will ask me why do you walk up and down when you take a break from the screen and then I will say I've got [epilepsy]" ... I don't want to have it in my mind all the time like, 'epilepsy, epilepsy, epilepsy' ... if somebody wants to hear about it or shows interest in it, I will open up about it . . . I'll share it with you once you show me a sign that you actually want to know about it or are interested in it, but I won't go around saying 'I've got epilepsy, I've got epilepsy', you know that type of thing, I won't label myself with that type of thing because I do believe that that's labelling yourself."

Mary goes on to describe the conundrum she faces when discussing the issue of driving and disclosure:

"I've got a driver's license and sometimes I feel when people ask me for a ride to a certain place or a workshop sometimes I feel ah I can't drive with people, should I tell them I am epileptic, you know that type of thing. If I normally drive with people nowadays I don't end up telling them, I just say, I always do this, and then tell them this is the password on my phone, I will say that is the medical numbers on my phone, just in case we are in an accident or that type of things, but I will say it in a joke kind of way, but in the back of mind I will always think oh my word, but then I get behind the wheel and I just say 'Lord be with us', but sometimes I think oh my word must I tell people I can't give people a lift sometimes. . . . That's the moment when, well it's not such a big thing, but then you freak people out, 'she says she's epileptic'. . . 'oh my gosh I am not going to drive with her', so you actually putting your own self at risk if you share too much because people freak out, if you share too much at the wrong time, you actually making trouble for yourself because sometimes people freak out because of one simple statement they hear and then they freak out about it."

Mary continually mentions how she leads a normal life today, and she doesn't let epilepsy limit her life in anyway. She identifies the biggest drawbacks for

her currently are the side effects of the medication. Mary has been nurtured in a special education school, and her epilepsy managed by qualified healthcare professionals and well-informed parents from an early age which could contribute significantly to Mary's perception of leading a normal life and insistence on not letting it limit her.

Enacted stigma can make a person with epilepsy feel rejected by society. Studies suggest that stigma-related stress contributes negatively to a person's wellbeing, and through socialisation PWE adopt these negative beliefs of themselves (Cree et al., 2006; Flowers et al., 2006; Link et al., 1989; Mays & Cochran, 2001). However, Mary's parents aimed to create a safe space for her to grow up in and tried to minimise negative experiences in her life. It is possible that the amount of nurture she received from her parents, and the schools she attended, equipped her with the necessary life skills to be able to ignore the enacted stigma she experienced and assisted her in coming to terms with her diagnosis and managing her epilepsy with confidence in adulthood. Many studies (Mushi et al., 2011; Ryan et al., 1980; Suurmeijer et al., 2001) have shown that health education and informal and professional support play a pivotal role in buffering against perceived "felt" stigma. Mary, having had this nurturing from early in life, most likely laid a good foundation which allowed her to embark on a journey of personal growth and to gain self-confidence and autonomy regarding her diagnosis in adulthood. Yet the negative experiences she faced, with having no friends outside of the family, being teased by community children, would have made this journey particularly arduous.

It is noteworthy that Mary tells of experiencing depressive episodes after a seizure has occurred. She explains how she would withdraw and avoid the place the seizure happened. Having a seizure may be viewed as "embarrassing" and from a clinical psychological perspective, it could be said that when she visits the place the seizure took place, this brings up all these unwanted feelings of embarrassment. Having endured teasing from community children, where they labelled her "crazy", would likely have reinforced this negative perception of what it means to have a seizure and

therefore evoke these negative feelings. In the same breath, depression disorders are a well-known co-morbidity in PWE. Yet, a significant portion of the clinical depressive symptoms of PWE often fail to meet the full DSM-IV criteria for a diagnosis and often go unrecognised and untreated (Kanner, 2003a, 2003b). Recent studies have suggested that depressive disorders in epilepsy are not a “normal reaction”, but rather are rooted in a biological cause (Kanner & Balabanov, 2002).

The issue about driving a car when having been diagnosed with epilepsy is an interesting one. Globally, there are different regulations across various countries. In South Africa, according to the National Road Traffic Act of 1996 you are not permitted to drive if you have uncontrolled epilepsy. However, apart from this regulation, deciding whether a person with epilepsy is permitted to drive is in the hands of the individual and their treating physician (Epilepsy SA, n.d.[a]). Mary’s daily internal battle about driving with passengers is a good example of a continual challenge she faces as a result of having epilepsy. Although she spoke about it light-heartedly, she is confronted with this decision every time she gets behind the wheel.

5.2.3. Family Dynamics and Shaping Social Interactions

Mary acknowledges that her family created a bubble around her to protect her from any negative influences. Mary, on the edge of tears, voice quivering, explains:

“To be honest I didn’t use to have friends, my parents never used to allow me to go out by myself, so friends were a no-no I think [my parents] didn’t want me to get hurt I never used to sleep out, they were concerned about it, they wouldn’t let me go sleep out unless it was family members that they know would really know how to take care of me if that must happen or should happen so ja I never used to go sleep out, but all that was explained to me, it was said to me it’s a no-no you are not allowed to go due to that, due to this, we don’t want you to get hurt because if people around you doesn’t know how to deal with it or handle you it might get worse or if you in a danger zone and it happens and that type of thing.”

“My family actually kept me around them continually so I never actually had the opportunity of experiencing people that is actually making me feel like [discriminated against] because my family always kept me around them, they didn’t give me the opportunity to be around different kinds of people and if they do trust different kinds of people around me they would actually educate them about it and tell them, explain to them how to help me or how to deal with me if I go into a phase of being quiet and I don’t speak and I just had one or two days ago or what they need to do to distract me. So I had a very good support structure that there wasn’t any time for people to actually treat me differently.”

“Whenever [the immediate and extended family] used to go on holiday together they were all very aware of the situation, so they didn’t treat me any differently or things like that. Even my cousins they knew exactly what to do, what it’s about, because my parents educated all of them about the situation because my father also has it and that was how I got it.”

“I think it limited me, like I couldn’t go out on play dates like normal as a normal child goes today. And going to the beach with friends like I said I didn’t go into a phase where I felt I was limited or wasn’t like a normal child because my family had everything in order. They would let my cousins come over and that type of thing so my family was basically my friends, my aunties’ child you know that type of thing, my cousins, my nieces, nephews.”

“Movies I used to go to, but like I said, I used to go with my family, I used to go with my cousins that type of thing, never with other friends. But sports I always use to swim at school and play tennis, but everybody was always educated about my situation and that they needed to be alert. Like I said my family had it all under control, they managed it correctly, they knew how far to go and what not to do to make me feel that I’m not being treated differently.”

“They gave me every opportunity I wanted, but I just didn’t have friends that was the only different thing, but I didn’t actually feel it or I wasn’t actually wise enough to look at it and take note of it, but I think it was the love and friendship I got from my family that I didn’t actually feel a need to have other friends.”

5.2.4. Standing on Her Own Two Feet

Mary became very emotional when she spoke of her journey of personal growth, which lead her to be self-assured in spite of the challenges she faced. She is adamant about and committed to standing on her own two feet without her parents’ assistance. When she was asked about her parents being too overprotective, she replied:

“to be honest I didn’t feel that way, but when I went to college, I felt that it’s too much – I need my freedom because I am all grown up and I know and I understand what it’s about. So back then I didn’t actually feel they were very overprotective, it was only when I went to college because that’s when I wanted my freedom The thing that changed in college was I started realizing that I need to take responsibility for my own life and I came to realize that my parents won’t be living for long, they won’t be there all the time so I need to prove to them while they are still there that I can stand and look after myself and ever since then that is what I am doing and I must say when I made that decision it helped a lot. I started getting my freedom and could actually lead a normal life, they trust me because I have proven that I am able to take care of myself and I am my own self It wasn’t an easy journey It was basically trying to show them I can take responsibility for myself and also proving to myself that I am able to do whatever I want to do if I put my mind to it and I have faith and I want to do it so basically it was to show them but also for my own self.”

“I never actually got the opportunity to [tell people about my diagnosis], my parents always used to take that responsibility away from me and I also feel that was why I feel when I went to college I wanted to take responsibility for my own self, my own feelings, my own whatever my

mind said and my heart tells me I want to take responsibility for that. There was many things that I felt enough was enough I am an adult now, so I wanted to take responsibility for my own self, so they always used to do that I never used to get the opportunity to actually explain to people Now, not many people know about it because I am living a quite normal life, I don't get it much, I manage my medication, I look after myself, I don't get it much so my family, I think my family is starting to forget about it at the moment so I also forgot about it to be honest."

It is common for parents with children with epilepsy to shelter their child, as Mary's parents did. Schneider and Conrad (1980) coined this behaviour "stigma coaching". There are many forms of "stigma coaching" whereby the well-meaning parents' overprotection of the child feeds into adulthood and the person with epilepsy continues to limit themselves as a result of internalising feelings of being less valuable, less adaptable, less dependable, less mature, less stable, less able to cope, less successful and less well-adjusted than the general population (Collins et al., 1990; Jacoby & Austin, 2007; Schneider & Conrad, 1981; Williams et al., 2003). Mary's well-meaning parents' "stigma-coaching" reinforced the idea that she needed to be constantly cared for. It appeared to create a strong dependence relationship between them. It manifested "felt" stigma in feelings of inadequacy, feelings of being unable to manage her own life and affairs. At college she began to realise this. She acknowledged that her well-meaning parents were overprotective of her and she has made a concerted effort to stand on her own two feet, to prove to both herself and her parents, that she is capable of looking after herself.

5.2.5. Her Father's Early Life

Mary spoke about the fact that her father has epilepsy too. She explains that her father was born with epilepsy and that he faced direct discrimination and copes with his diagnosis very differently to her:

"Mom only found out once they were married, he didn't share it while they were dating, I do feel back then he was scared because people weren't educated then and even up today people are not educated

about it, I was just lucky and fortunate enough to be around a mother who educated everyone around her about it Because many people look at it as a negative thing because if I listen to my father's story of when he had it you just hear negativity about it and he used to get it on the roads and streets and then he and my mother were just married for a few years and then she would go and help him, people wouldn't help him, she would actually have to go and help him, and go leave her job to help him, yeah but people weren't educated back then about it Back then people used to have silly beliefs, I could remember my parents mentioning a few, like it's a mental thing, people used to say lots of silly stuff that didn't make sense so that why I say it all comes down to education, people are not educated enough to understand certain things which can destroy someone else's emotional ability [My father] is not as open as I am, he doesn't deal with it the way I do. I think my mother saw the type of person he is and how he deals with it and I think when I was younger and first diagnosed she just said to herself I don't want that for my child. I don't want my child to go through a childhood like that because obviously she knows who she's married to and maybe he shared with her all the difficulties and challenges he went through."

It is remarkable to view the difference in how Mary and her father manage living with the same disease. Her father is less open about his epilepsy, possibly because he had faced much more discrimination and enacted stigma than Mary. She explains that people were less informed and educated when her father was growing up, and therefore the community held misbeliefs about epilepsy and reacted negatively towards him. She explains how her father's extreme fear of judgement lead him to not disclose his diagnosis with his fiancé (her mother), and her mother only found out once they were married. In contrast, Mary grew up in a nurturing environment with a family who was well-educated about epilepsy, and in appropriate situations she feels open to disclose that she has epilepsy. Studies have shown that the level of "felt" stigma experienced is mediated by numerous factors such as perceptions,

education, and professional and informal support (Ryan et al., 1980; Suurmeijer et al., 2001).

5.2.6. Conclusion

In summary, Mary's childhood was shaped by frequent admissions to hospital, attendance at a special education school, facing enacted-stigma – being teased by community neighbourhood children, having no friends outside of her family, and having well-meaning parents who adopted “stigma-coaching” roles which in turn developed “felt” stigma feelings of inadequacy. She found it incredibly difficult to break away from her parents' sheltering and to learn not to take what people say to heart. She has done an enormous amount of self-work in personal growth, and it has had immense benefits for her, allowing her to build self-confidence, autonomy and control of her own life.

Mary's father has epilepsy and her parents received a large amount of informed care from the hospital she attended, which together prepared her family to manage her epilepsy. When she was younger, she did experience depressive episodes after a seizure had occurred, where she found herself withdrawing. She is open to disclosing her diagnosis in appropriate situations, although she doesn't like to dwell on it as she feels this would in turn give her a label (or identity) of being “epileptic”. She does not appear to fear outright judgment, but there is a hint of fear in her explanation of how to deal with passengers riding in her car. Mary has faced both elements of enacted and “felt” stigma, but through a nurturing and supportive base she has made massive strides to having autonomy of her life and confidence about living with epilepsy.

5.3. Case Study 2: Lerato

5.3.1. Background

Lerato is a 19-year-old female. She is currently enrolled in an undergraduate program at a local university. She lives with her parents in an urban suburb in a middle-to high socioeconomic community in Cape Town. She had her first seizure when she was 12 years old. She has a younger brother, who is 4

years her junior. She does not experience seizures frequently, but has had a seizure in the last 12 months.

5.3.2 Being Informed and Supported

Lerato's first seizure happened when she was in Grade 7 when she was 12 years of age. She is markedly unconcerned about having epilepsy. When asked how she felt about first receiving her diagnosis she recalled:

"It wasn't anything bad, I wasn't upset or anything or angry or whatever, I just knew it, said okay I am epileptic, need to take my medication, need to take care of myself, if anything happens need to record it and stuff, as soon as my prescription is done then I have to go the neurologist and get a check-up also, because if I have a seizure, because I am on medication, he may need to increase the dosage then, if not, decrease it, and see how it affects me. I know it's going to be a thing for life, but I am not upset."

She admits that before she was diagnosed with epilepsy, she didn't know much about epilepsy:

"Didn't know what it was, hadn't been around anyone who was epileptic, I wasn't that informed, it's not like normal, it's not like you see it everywhere."

She also remarks that she does view epilepsy as a disease which is not normalised by the public like, for example, diabetes is:

"It's not a normal thing like diabetes."

However, she explains that her parents are and were hugely supportive and are very involved and attentive in the daily management of her epilepsy. When she was first diagnosed she remembers how unconcerned she was because she felt entrusted to her parents' care:

"Because it happened when I was so young, I was 12, when you that young, you don't think that much, for me I was sick, I was in hospital, but now I am on medication and I am fine. If it were to happen now, it might be a bit like why is this happening, but back then when it initially

happened, I wasn't like what's going on it was just sort of this weird thing happened out of nowhere. Like when my parents said they didn't know why, I think I didn't think further than that."

She explains that the doctors don't know why she has epilepsy, but it does not bother her:

"Wasn't really super affected, but when it happened, I couldn't find out why so like there's no tumour or anything, so we don't know why I am epileptic or why the seizures happen, they just do."

Lerato believes she is accepting of her diagnosis as a result of being fully informed and having friends and family who are informed. She explains she is comfortable telling people she has epilepsy, however, she does make a distinction about being "open" to telling people she has epilepsy, versus being "not ashamed" about having epilepsy:

"I would be comfortable and I am not ashamed to tell someone So it's not like the first thing I tell, but I am not necessarily ashamed, because for me it's normal, there's nothing I can do about it and I guess all the people I am with understand it, as like my mom told me when it comes to people in my culture, like black people in general, they actually think of seizures and epilepsy as like the devil's work and witchcraft and stuff, so for us, I sort of believe with whatever my parents come up with, obviously they know it's scientific and stuff, so I have that in my head, whereas you get other people that think all of this random stuff, I think if I had to interact with those people that thinks it's like devil's work and witchcraft then I think I wouldn't really be like 'ja I am epileptic', the people I am with are well informed and understand."

Lerato took a moment to think back and recount when she had her first seizure:

"I had the seizure at school, so I was like playing sport, I was just there, like I don't remember exactly who noticed what, but like my father came and we went to hospital. I was at school and then went to the nearest hospital, then I came back a few days later, and my

classmates asked are you okay what happened, so there was like that.”

She recalls that her classmates' interest in her made her feel like they cared:

“like it felt nice that they cared and checking on me, I didn’t expect them to come check on me.”

Lerato is distinctly unaffected by her diagnosis, and this largely could be a result of having a comprehensive social support system in both friends and family as is recognised in the literature (Mushi et al., 2011). The literature reports on how through socialisation PWE may adopt negative beliefs of themselves (Cree et al., 2006; Flowers et al., 2006; Link et al., 1989; Mays & Cochran, 2001). It is possible that this could also be true of the reverse. Lerato is surrounded by informed people who treat her as a peer and do not single her out by treating her differently. This positive socialisation could influence her to adopt a positive perception of herself.

5.3.3. Everyday Life

Lerato is not acutely worried about people finding out that she has epilepsy and is unashamed about sharing her diagnosis with others. She does not fear judgement, she rather acknowledges the benefits of those around her being aware and informed:

“It’s not like the first thing I say when I introduce myself, it’s not something I openly say, but maybe say to my friends if we were talking about related stuff, like I might say I am taking medication and then I would reveal it I guess But I know it’s actually dangerous because I need to inform people who are around me just so just in case anything happens I know I should do that but it’s not the first thing that comes to mind when I am interacting with people. But people I stay with I need to inform them because if anything happens, they can notify my parents.”

When asked if her parents treat her and her brother differently she responded:

“No, no, no” very emphatically. When asked if she feels she has ever been

mistreated by anyone around her because she is epilepsy, she exclaims:

"Not at all. I think the only thing, not with the housemates, but when I was in high-school, when I told someone, they didn't understand what it meant, maybe something like that with someone, some people where they don't 100% understand what it means. So, I think with that also they don't really get super stressed, or whatever, if this is the first time they are hearing that someone they know has the epilepsy then they not really, they don't really care much, they don't get super stressed or overprotective . . . which I guess helps me because then I don't feel different, no one feels the need to look after me. The only thing is my friend was asking questions, but like stuff me myself doesn't know, and said maybe next time you see your doctor ask this, I think he's just interested in knowing different ways it can affect me."

Lerato acknowledges that her acceptance and perception of living with epilepsy has, and is, influenced by those around her, and she does not fear judgement from them, as she knows they are well informed:

"I'm not uncomfortable at all, but like I said it's not necessarily the first thing I am going to tell people but I guess in general how informed I am it's okay whereas like I said culturally some black people they just think this is devil's work and witchcraft and stuff but I guess I am blessed to be lucky enough to not be so ignorant so that helps a lot also whereas like if I was misinformed and not having medication then I guess it would be something else I am in university so the people around me are more informed, more educated. Don't ask ignorant questions. But if they were asking questions that were stupid then I might get more annoyed."

Lerato also alluded to the fact that although people may be aware and informed about epilepsy, they only partially understand what epilepsy is, for example people generally associate epilepsy with having grand mal tonic-clonic seizures:

"like people think it's just like people just fall on the floor, they shaking, they got like, like something out of the ordinary just happens."

Lerato is unconcerned about her epilepsy diagnosis and ensures she does not let it limit her:

“I won’t limit myself to what I can do I’m just thinking what can a 17-year old do, not, what can a 17-year-old with epilepsy do Some people let it limit them, I lived my life normally, I play sport etcetera. I don’t let it limit me Like I got my driver’s license, I won’t let it stop me, I will cross the road.”

It is noteworthy that Lerato refers to the public’s perception of epilepsy as thinking seizures just occur in one form, where a person with epilepsy would fall to the floor shaking violently. Epilepsy is a spectrum condition with patients varying in seizure types and control, where not all seizures are overtly visible (Fisher, 2014; Fisher et al., 2014). Lerato’s seizures are less obvious to the untrained eye, and therefore perhaps having a less visually obvious seizure type allows Lerato more protection against enacted stigma and therefore negative reactions. Jacoby and colleagues (Baker et al., 2001; Jacoby, 1992, 1994; Jacoby et al., 2001) have shown that there is a direct relationship between epilepsy type and severity and “felt” stigma.

5.3.4. Where Differences Arise

Lerato does pick up on a few aspects of life where she feels that having epilepsy means things are slightly different for her than someone without epilepsy:

“You know what does sucks, is that headaches is a thing, like medication and sleep just to sort of wear off the headache would be easier if I stayed on campus whereas I stay at home [40 minute drive from campus] so I can’t just up and go, I can’t just go home, unless I have nothing to do, then it’s okay I see myself go home, other than that I just have to deal with it One of the things my doctor said is I can’t have alcohol, well I can, but not too much, things like that, because if I go out with friends, like a birthday party, like I can have, but not too much, then in that case I do need to inform them, because at this age at university, it’s a thing to go out and drink or whatever, I am not like a

hardcore partier, but when in that setting, I myself know okay you can have, but not too much, just control yourself.”

Lerato does acknowledge that she does worry a little bit about when the next seizure may occur:

“like before I could even drive, that was one of the things my mother asked my doctor, is it safe to drive, for some people that’s a big thing, even for a split second something could happen Or what if I’m crossing the road, so just like situations where you need to be aware fully, then I am bit worried.”

5.3.5. Conclusion

In summary, Lerato is very blasé about her diagnosis, she feels it does not negatively impact her life in anyway. She does not experience seizures frequently, but has had a seizure in the last 12 months and her seizures are also not overtly visible. She has parents and friends, who are all well-informed and supportive of her diagnosis and treat her no differently to her siblings or peers. She was also enrolled in a mainstream school and reports never experiencing enacted stigma. She mildly worries about when the next seizure will occur, but doesn’t let it stop her living life. I believe all these buffers have insulated her from overwhelming feelings of “felt” stigma. She is open to disclosing her diagnosis and does not believe epilepsy limits her. She has a very positive mindset about living with epilepsy.

5.4. Case study 3: Patience

5.4.1. Background

Patience is a 40-year old female. She has five sisters. She has been married to her partner for 13-years. She has a son (whose biological father is not Patience’s current partner) who is 22 years old. The highest level of schooling she completed was Grade 11. She attempted to do practical training as both a welder and a hairdresser, but never completed the programs due to her epileptic seizures. Patience had her first seizure when she was 19-20 years old. She remembers it happened within a year after her son’s birth. In 2017 alone, she had experienced about 4-5 seizures. On average she has about 2-

3 seizures each year. She grew up, and still lives in, a low-socioeconomic community in an urban township in Cape Town. She is currently unemployed.

Patience was not a first-language English speaker. Although she could speak English, her ability to express herself in depth in English was a struggle for her, and it was a challenge to me to interpret the interview. Therefore, I needed to rephrase the questions in multiple ways to determine that she understood what was being asked and I would also need to frequently echo back to her what I thought she was trying to articulate to ensure I was not making my own assumptions about her feelings and perceptions. We developed a good rapport, and she corrected me where I incorrectly understood what she was trying to convey.

5.4.2. Why Me?

Patience's first seizure occurred when she was about 19-20 years old. For many years Patience lived unsupported, with many unanswered questions about how to manage her epilepsy. After her first seizure, the healthcare workers she initially went to for help at a community clinic in Cape Town provided her with an accurate diagnosis, but her medication was poorly managed, and they did not offer her any social support: *"they never told me what is going to happen, and what all these will do to me."* Only once she was able to come to medical specialists, several years after her first seizure, at a tertiary hospital in Cape Town, was her medication appropriately managed and she was offered more support around the management of epilepsy. Patience remarks how very happy she was to receive more information about epilepsy. She explained she had so many unanswered questions about what she can and cannot do as a result of having epilepsy: *"I said to the doctor I am very happy talking to you to give me more advice, like can I still go on, if I wish to start studying, thinking, these things."* Patience does also attend a support group for PWE lead by a local NGO, however, it seems there is a piece missing in her support program. Although she is very appreciative of their support, it sounds like she is looking for more one-on-one care, as she was very eager to have the opportunity to sit-down for this interview and she also made several comments about wishing people around her would take

more of an interest in her, and ask her about how she feels about her epilepsy (or “sickness”): *“I think it’s very important because I couldn’t wait talking to somebody, giving more advice about this sick and maybe when or how or what they can do and when it can be finished and so on. [The support group] don’t exactly ask us. They rather ask us to be going with people with our sick, with this sick, like going and sitting.”* She used to believe her epilepsy would one day go away: *“and I ask the doctor what he think about this sick, is [epilepsy] going to be for the rest of my life”*, but the doctors explained that it is with her for life. She recalls how people have said to her that epilepsy is possibly hereditary and may have resulted from a genetic predisposition she may have. Patience feels upset that of all her five sisters, why does she have epilepsy: *“I weren’t happy, I was like why me with this family sick.”*

Patience consistently makes an effort to keep her diagnosis hidden from other members in her community: *“Many people don’t know about this sick, that’s why I don’t like sleeping at people’s places, I like being at home.”* She remarks on her “acting”. She describes how she puts on an “act” to hide the fact that she has epilepsy: *“like you quiet, there’s my smiling, like you acting as nothing is going on with you.”* She believes that she does an excellent job of “acting” like a person who is not “sick”. As a result of her ability to make people believe she is “not sick”, she thinks people will be “shocked” to find out she has epilepsy (or is “sick” as she explains). She tells me that nobody at her church knows she has epilepsy and she wonders what they would say if they find out: *“friends and where you go to, like church things and so . . . people they don’t know for me which is a sick person or so because of my acting my smile and as if nothing. I will just say agh I’ve got a bad headache and these things, but not to say I’ve got this sick”*. Patience identifies as a “sick person”, but is continually “acting like a non-sick person” in an effort to preserve her secret.

Patience describes how her medication is her safety blanket¹⁰. She takes her medication with her wherever she goes. She feels safe when she has her

¹⁰ “security blanket” is a term used to describe an item that provides psychological comfort

medication with her and will feel anxious about a possible next seizure if she hasn't got it with her or if she forgets to take it:

"in the morning when I take it, everything's okay, I feel like normal . . . it's only when I didn't take it, that I worry I will get sick . . . everywhere when I go, I put my medication in my bag, because maybe I can come home late and now I didn't, I feel so nervous sitting by someone else's place, I wish to get home, in case something happens to me If they invite me, I'll go, I'll just make sure I take my medication."

Patience highlights how there is significant stigma around HIV/AIDS and TB in her community. She comments on how badly people who are HIV-positive or have been diagnosed with TB are treated in her community and fears she would be treated the same if people knew she had epilepsy:

"because I think maybe epilepsy is like with somebody who's got these AIDS and things and not wanted anymore It's like somebody who's got these HIV sickness, the way I feel, and the way I think, it's like, how they will think about me, always making jokes of me". She also explains how the healthcare workers at her local community clinic are also very unsupportive and unhelpful. *"because it's the way they treat, not treat you, but their styles is also against you, like you nothing worth it, you've got that sick, that why I said to you, I'm so shy and worried, people mustn't find out how I got this sick because I feel like somebody is like nothing worth it anymore and so on."*

A group of researchers explored perceptions of doctors working in primary care settings in Cape Town, South Africa (Keikelame et al., 2012). Their analysis revealed that epilepsy is poorly managed in South Africa, and the lack of attention to epilepsy management is a serious concern and, in some instances, has led to violations of health rights.

Patience feels most comfortable when interacting with people who have also been diagnosed with an illness or disorder. She finds a sense of safety and relief from fear of judgment:

“I am always there for people who is sick, advising them and all these, because I thinking about myself, I am also sick, I want to be there, because if anything might happen to me, they can come to me because they can’t blame and talk bad about myself that’s why . . . I used to do homecare, nursing, part-time homecare nursing, go to people’s places, up and down with them, most of the time, sitting with them, chatting, advising . . . I know how to speak and make people most comfortable, because I think of myself, what can happen, if anything bad happen to me in front of them, they also must feel sorry for me, and I won’t feel maybe embarrassed, because this thing I do feel embarrassed what happen, did they get the same way, the way they get their sick.”

Although Patience is infinitely worried about people finding out she has epilepsy and judging her, she still doesn’t let that fear of judgement stop her from leaving the house. She does go to church, she walks to the shops and around her community and will visit family and her family’s friends’ houses. She says she:

“mustn’t be afraid and scared it might happen, because that where it started.” Although at the same time, she does say she is not happy leaving the house, and when she does leave, she makes it quick: *“I just feel like I am more happy at home doing myself like working and all these and sitting with my music sitting nice comfortable alone . . . if I must do, it’s like one two I am out of the shop . . . the way I feel tired very fast and with that tiredness that make me think I am going to get sick.”*

Patience firmly believes that she cannot attend school or study. Her husband and family share this belief as they encourage her to take it easy. As previously explained, it is very common for family members to become “stigma coaches” (Allotey & Reidpath, 2007; Shorvon & Farmer, 1988). She

worries that the associated stress and exhaustion (or *“thinking”* as she refers to it) will cause a seizure. However, she has not let that stop her from trying. She has enrolled herself in two practical training courses before, one in welding and the other in hairdressing. She did however drop out of both as a result of her epilepsy. She dropped the welding course, because she had a seizure during her practical, and this led people to believe that this type of work could be dangerous for her if she were to have a seizure while operating heavy machinery. In her final year of her hairdressing course it became very stressful and her frequency of seizures increased. She tells of the first day of her hairdressing course: *“all of us had been so like looking nervous because we thought it was only going to be something about hands, myself I thought it was going to be something of hands not thinking, now all these in my head ... I had to start thinking a lot, why, what’s going on here, and myself, and that’s where it start.”* She shared a memory of when she was at the height of her hairdressing studies and she had a seizure at the train station on her way to class. She explains at the time she was working very hard. She was getting up early to read her textbooks, and then travelling by train to class. She emphasised that the reason she had wanted to enrol in hairdressing is that she believed the training would be more practical (or *“be something of hands”* as she refers to it). She claims she had a seizure as a result of all her hard studying for class (or *“all this thinking”* as she put it) and that is why she then chose to discontinue the training. However, she is determined to further herself, and her next ambition is to try finish matric, yet she is very anxious about enrolling: *“I’ve applied for next year by doing matric, but I am so worried, I am so worried, like how I am going to study again, because when I am studying with books it happens.”*

Patience hears stories of others who have been diagnosed with epilepsy, who go on to lead “normal” lives, and this inspires her. She found out that a fellow member at her church has epilepsy and that he nevertheless holds down a good job. She explains knowing this makes her feel she could do the same:

“I always think like why can’t I be like someone else, who’s thinking, and surprise for me when I’ve heard about there still students with this

sick that's why I do my best to go myself and see if I'm going to survive and so on . . . like how can they think and myself I can't think."

She reflects on a story her husband shared with her about another member of their church (who she knew). Her husband told her this church member also had epilepsy. Patience said she felt *"surprised"* and *"shocked"* to find out that this church member also had epilepsy: *"I was surprised when my husband said to me in church, one of his friends got this sick, the same as me, I was shocked, I thought I'm the only one."* Patience remarks on how her surprise became inspiration: *"he's still working, the type of jobs he's doing and all these and so on ... that's why I said oh now I can go to college, I can think, I can work."*

Patience has not been fortunate enough to have led a life where her epilepsy was well managed. She lived many years uninformed about her epilepsy and was surrounded by others who were equally uninformed about her condition. Mushi and colleagues have highlighted how a lack of education contributes to stigma (Mushi et al., 2011). She has led a relatively lonely journey through life with her epilepsy, and has had to face many internal battles on her own. The community she lives in carries significant stigma around other health-related issues, which makes her fear for the treatment of herself. Even though Patience's seizures do occur in the evening, often when she is sleeping, the socialisation in her community has influenced and formed the negative beliefs of herself. This socialisation phenomenon has been remarked on by numerous authors in the literature (Cree et al., 2006; Flowers et al., 2006; Link et al., 1989; Mays & Cochran, 2001).

5.4.3. Navigating Relationships: Family, Friends, and Partner

Patience and her partner have been together for 13 years. Her current partner is not the biological father of her son. Yet Patience's son and partner get along very well, and her son refers to him as "Daddy". She assures me they both love him (her partner) very much, and that he spoils them and takes very good care of them. She reflects on how he will bring her her medication if she has forgotten it at home, and shares in her worry that the stress and

exhaustion of her studies will increase the risk of her getting a seizure. She goes on to reminisce how she and her partner met:

“we meet somewhere in Cape Town, I was walking around and so, that’s where I met him, so he ask me where I am staying and everything, and now coming home, to my place to his place, now he can see where I am getting off my taxi and so on, and he came by surprise to visit, and I was so upset, I said no, I was very upset, I argued with him about these things, and every time I got sick he be there, and I felt very embarrassed like ah this guy mustn’t find out my sick, what is he doing here . . . I thought he was not going to be fine about [my epilepsy], I thought he was going to laugh and stay away from me . . . one of my friends said no man you can take him for a husband, he’s a very very very good boyfriend and so I took him for a boyfriend, and so I said to him, fine, I can be your girlfriend, and then he begged me for marriage after that and I said oh no for us it’s like this, you must first be engaged and then married.”

She goes on to talk about when he first witnessed a seizure of hers:

“when he saw, that’s where I agree, okay I’ll be your girlfriend, he did, but myself I didn’t [feel good], I was so scared, what is he going to say, what is he going to think, because I think this sick, is like an embarrassing sick, a nothing wanted person, that why I still feel shy and wish I can leave it.”

Patience then starts explaining how her family started becoming more involved with him than her, and she thinks this is because she has epilepsy. She exclaims how frustrated she feels, because she feels that her parents treat her as if she is not capable of managing her own affairs. Often when they visit, her family will ask her husband how Patience’s health is:

“I said to my mother yesterday they make me more feel like I’m the daughter-in-law and [my husband is] their son and I feel maybe it’s for me like I saw these other people, these epileptic people, it’s like you know you feel like so different you can’t think and they want nothing to do with me so they must work with [my husband], not with me and all

these things Like I said I feel like my mother's daughter-in-law and he's the son and most of all they won't come to me, they'll come to him and talk things and think maybe because of my sick does this people think maybe I can't think or what why they going to him and not me, I think maybe my sick or what, make me feel very embarrassed like my sick and these things".

This is typical of "stigma coaching", where feelings of being less mature, less dependable are entrenched into adulthood (Collins et al., 1990; Jacoby & Austin, 2007; Schneider, 2009).

Patience explains that her husband is the one who offers her the most support. However, there are negative forces impacting on their relationship:

"One thing he don't understand is like sex because I used to read a book about epilepsy where someone can get frustrated upset and no feeling like sex . . . I don't know who to blame, the tablets, or me, but it is after my tablets I just feel for nothing because I like to be like lonely thinking in front of my TV because it makes me like nice sleeping, I don't even have this feeling for like I must start reading . . . but after taking tablets I'm like no I can do nothing now I must go lay down now and resting."

She also has doubts about the stability of their relationship and, after 13 years of being together, she still feels insecure about having epilepsy:

"I thought maybe he don't love me because maybe my sick. I'm still feeling nervous and little bit out of place because even myself the way I feels like my husband don't love me anymore like he take more care of other people than myself and there's nothing I can do because of my sick, I'm afraid, maybe leave him, I think like maybe he think these things, if I leave him and run away, I can't because whose going to look after me, whose going to take care of me." She reflects: "I never thought I would get married." Patience fears judgement and that no one will love her because she has epilepsy.

5.4.4. Feelings, Thoughts and Emotions

Patience speaks about being grateful that many people don't know she has epilepsy. Her family and several close friends are aware she has epilepsy, but others in her community, such as fellow church members, and students she attends class with are unaware of her epilepsy. She continually remarks about how *"lucky"* she is that many people don't know that she has epilepsy (or about her *"sickness"* as she refers to it). She explains that commonly her seizures tend to occur during the evening, often when she is asleep. She exclaims she feels lucky that this is the case: *"I feel lucky it is the time when I'm sleeping and not in front of people"* as she has a constant *"fear"* that people will find out she has epilepsy. Her seizures mostly occur at night, when she is away from the public, and this affords her a sense of safety in that her secret can remain hidden from those around her. Patience recalls her *"disappointment"* and *"embarrassment"* when last year, during her hairdressing studies, she was at the end of her second year (of a 3-year program), and during one of the classes she had a seizure in front of her classmates:

"last year in school, my first time, it happens, in school. From there I have been very disappointed because I feel so embarrassed. It's like, okay nobody knew, it's just like my teachers know, but now these students they think maybe it's because of my nerves and I am a very nervous person because they don't understand. Now I've been so worried, these people mustn't talk to the other students about what happened to me, and what's going on, and all this."

Patience chooses not to disclose that she has epilepsy as she is fearful of judgement. She feels very isolated by living with epilepsy, and because of this *"sickness"* she feels *"very very lonely"*, *"frustrated"* and *"sad"*. She feels that she cannot talk to anyone. When asked if she feels comfortable to talk to people about having epilepsy, she said *"no"*. She explains:

"I guess the way I feel about it, is that they are going to laugh at me, and I won't be like a person, like the way they are . . . I used to get sick in front of people, now it's like they dislike me, the treat against me, even if somebody looking at you, I feel like then I feel like maybe I

got sick in front of them I feel embarrassed and worried that anyone might hear about my sick and maybe how they will feel about myself.”

Her worries even extend to that of her husband, she fears he will be negatively judged on account of her. She says she doesn't “*want to embarrass [her] husband, [by] showing people [she is] a sick person.*”

Patience struggles substantially with the expectant fear of judgment from people finding out she has epilepsy:

“even at school, I be so worried, feeling like embarrassed something may happen I want to be home by 6 or have my tablets, now I'm sitting with [my friends] and they see me not talking, and my smile, and I'm so worried, and I think, maybe I did get sick in front of them.”

She recalls an experience where she had a seizure at one of her mother's friend's house:

“because what happened one time when I was being at a friend's house, and it happened, it be my mother's friends, I don't know if they know or what, about this, because I've been there that one time, at night, and come there, and I never went back again to them. Even when they saw me, they didn't even talk to it about me and ask me questions and so on and so I think ah they know about and what's going on and so on I know these type of people is like talkative people, party together, now they will talk about me, all these, but I don't know exactly what . . . from there I never went to their places again, we only just greet each other when we pass and so on and I feel so like heartbroken, did they talk about me or what, but I can see their styles also with me it's very nice, very talkative, they didn't ask me; ‘how you feel?’”

She recognises that perhaps many of these feelings she has regarding people viewing her negatively are not necessarily reality, but rather the way she perceives it to be:

“maybe they mistreat me and because maybe I would feel very embarrassed, shy, start staying away because maybe the way they might look at me, you know the ways you think of yourself, maybe they would feel so and think and talkative and ask can’t be her and is it really.”

She finds living with a constant fear of judgement exhausting. She explains that this constant fear of judgement is why she wishes this could all stop. She explains that when she talks to the doctors, she gets excited, as it brings hopes that it will end the seizures, and she will then no longer have to live with this fear. However, Patience says she doesn’t feel like she can’t enjoy life.

5.4.5. Conclusion

In summary, Patience has about 3-4 seizures a year on average. When Patience had her first seizure and was initially diagnosed with epilepsy, it was poorly managed, and she did not have access to information about how to live with and manage her epilepsy. She was left with many unanswered questions for several years, having to quietly battle her struggles on her own. On top of not having access to adequate information, she felt rejected and judged by the community clinic’s staff, where she would normally need to go to seek help. Patience has not come to terms with or accepted her diagnosis. She frequently makes comments about wishing she did not have epilepsy. She has a significant fear of judgement, which comes up frequently. She continually worries about what will happen if people find out she has epilepsy. She has had a number of seizures in public places in front of people, which tremendously upsets her, as she now fears these people are judging her, although she does concede that perhaps this is only her perception. She therefore does not disclose that she has epilepsy to anyone, but rather actively tries to hide it from those around her. She firmly believes that she does not have the ability to study, as she feels the exhaustion and stress of studying will cause her to have seizures. This limiting belief is shared by her husband and immediate family (parents, and sisters) who try to shelter her from over-exerting herself to prevent a seizure occurring. Furthermore, she acknowledges how her family disempowers her by always going to her

husband instead of her about matters. She feels they think it is because she is not capable because she has epilepsy. She has adopted a “*sick*” identity where she likens herself to those in her community with other illnesses and fears the same judgement, and explains how she feels safer when with other people who are “*sick*”. She also mentions how she is shocked to find out a member of her church also has epilepsy, as she had perceived him to be normal, and now she finds out he too has epilepsy, and therefore he should be perceived as sick, but this doesn’t add up with her perception of him.

5.5. Conclusion

These three individuals were all from different backgrounds and communities and have experienced living with epilepsy through different lenses. They reported a broad range of subjective experiences and perceptions. There are both similarities and differences in their realities of living with epilepsy.

Mary and Lerato were both fortunate enough to have been brought up in families who were well-informed about epilepsy and received tremendous amounts of support both from healthcare staff and their parents. In contrast, Patience went many years having several unanswered questions about epilepsy and received very little or no support. Mary is the only participant to have experienced enacted stigma, being teased by community children while growing up. Yet, Patience remarks how she has witnessed community members treating others who have illnesses badly and she fears the same treatment. Lerato, on the other hand, has lived a life where no one treated her differently, and she has never had to fear being treated differently. Mary and Patience both speak of the stigma coaching by their families, that is, the well-meaning, overprotectiveness of their family members. Mary has had a harder time breaking this bond of dependability on her parents as she was diagnosed as a young child and her parents carefully organised her life to protect her from any negative forces. Patience on the other hand was not overprotected, but rather since marrying her husband has found that the family will defer to the husband rather than herself when querying her well-being. This frustrates Patience as she feels her family think she is not capable. Lerato’s seizures appear infrequently and are not overtly visible, while Mary’s seizures are also

infrequent, but are very obvious. In contrast to this, Patience's seizures occur fairly regularly (3 to 4 times a year) but mostly at night when she is sleeping. Mary and Lerato both have come to terms with their diagnosis, and believe their mindset has a lot to do with that. Fortunate circumstances have likely influenced their mindset, for example, having supportive families and being well-informed about epilepsy. Even though Mary faced teasing and name calling, her parents protected her from other harms of life and gave her a fun-filled life by allowing her to make friends with family members. However, Mary faced a treacherous battle with breaking the dependent-bond with her parents during her adulthood years. However, Patience is not accepting of her diagnosis, and remarks "why me", and puts a lot of energy into hiding her diagnosis from those around her, fearing constantly that people will find out.

Studies show that stigmatisation of epilepsy is mediated by factors such as education, medication side effects and social support (Baker et al., 1997; Mushi et al., 2011; Ryan et al., 1980; Suurmeijer et al., 2001). These factors have been shown to influence the way these three individuals experience living with epilepsy. Lerato, having had a multitude of positive factors influencing her perception of her reality, has led to her experiencing very low levels of "felt" stigma. Mary, having also a multitude of positive factors, yet peppered with some significant challenges, has had to do a lot of personal growth in order to feel in control of her life and experience lower levels of "felt" stigma. Lastly, Patience, who has not been afforded the same buffers against stigma as Mary and Lerato, still struggles daily with the feeling of "felt" stigma.

Chapter 6

Conclusions and Recommendations

6.1 Introduction

The purpose of this study is to describe the experience of living with epilepsy and the associated stigma. Theory of social stigma defines stigma as an “undesired differentness” and refers to a loss of status and social exclusion of the stigmatised individual (Goffman, 1963). Public misperceptions of epilepsy combined with visible symptoms (i.e. seizures) which appear “violent” in nature are likely the basis for epilepsy-associated stigma. Epilepsy-associated stigma consists of varying forms of stigmatisation, including enacted, “felt” and courtesy stigma (Scambler & Hopkins, 1990), and occurs both at the institutional and individual level. The nature of epilepsy-associated stigma is reportedly different between countries, and also between communities within the same country (Doughty et al., 2003), highlighting that stigma is shaped by differences in education, cultural values, access to healthcare, quality of care, and legal rules, among other factors (Pescosolido et al., 2008). The difference in experiences of stigma between communities raises the need for further research to identify the beliefs and challenges faced by people with epilepsy in a defined community.

There is very little research on epilepsy-associated stigma emerging from South Africa. Following a qualitative method, using an ethnographic approach, an initial pilot study was conducted which involved seven participants, and thereafter an additional three people with epilepsy were recruited and more in-depth interviews were conducted. The primary objective of this study is to describe the lived experience of living with epilepsy to explore the associated stigma.

6.2 Key Themes

6.2.1 Contributors and Buffers of Perceived or “Felt” Stigma

Key themes which have emerged across the pilot study and in-depth interviews as making an impact on epilepsy-associated “felt” stigma include, participants’ social support, the public’s understanding, incidents of enacted

stigma, the fear of enacted stigma and daily reminders of being “different”.

6.2.1.1 Social Support

Social support structures have emerged as an influencing factor in epilepsy-associated “felt” stigma in participants of this research. Participants experienced varied social support structures, and experienced varied consequences as a likely result. Three contrasting environments emerged in this group: participants who were unsupported, participants who were overprotected and participants who were treated no differently to their peers without epilepsy.

Patience and Participant #2 report having deprived and unsupportive environments while living with epilepsy. Patience reports having seizures only 2-3 times a year, while Participant #2 reports having 2-3 seizures a month. Patience had very little support from healthcare workers and lived many years with unanswered questions about how she should manage her epilepsy. She also lives in a community where people who have HIV/AIDS are stigmatised. She equates herself to someone who has HIV/AIDS, and therefore fears the same treatment in her community. She also describes how her family tend to defer to her husband instead of her, and she believes this is because they think she is not capable as a result of having epilepsy. In addition, she feels that nurses at the community clinic she attends treat her like she is “worthless”. She finds relief in spending time with people, who are “sick”. She feels safe and free from judgement around other “sick” people, and continually remarked on how she is always “acting” like a “normal” person to hide that she has epilepsy. Patience explains how epilepsy impacts on her marriage, and “studying with books” is too difficult with the increase in seizures that occurs, and so she prefers to remain at home rather than being outside in public. Participant #2’s parents died and therefore she was cared for by her aunt who she explains treated her like a child her entire life. Participant #2 reflected on all the things she feels she could have accomplished, but reckons that epilepsy has held her back in life and is the reason she hasn’t accomplished much in her lifetime. For instance, having her son taken from her as she was deemed unfit to care for him because of the frequency of her

seizures. Participant #2 likens herself to a person who would be admitted to a psychiatric facility, and constantly referring to herself as *“not so good in thinking”* and *“[can’t] think so well for [herself]”*. Both these participants identify with being “sick” and show low self-esteem and a lack of confidence in their ability to accomplish things as a result of their epilepsy. The adoption of the “sick role” is reinforced by “stigma coaches” such as healthcare workers and family members whose advice and attitudes impose restrictions on their daily activities. In addition, neither participant is comfortable disclosing that they have epilepsy, as they fear judgement. This is likely a result of being uninformed and being supported by others who are uninformed.

In contrast, Mary and Participant #4 reported their parents were well-meaning yet over-protective. Participant #4’s last seizure was 2 years ago, and Mary’s last seizure was over a year ago. Their parents imposed restrictions on them because they had epilepsy, and controlled and ordered their childhood very carefully. For example, they were not allowed to attend sleepovers in case they were to have a seizure. They both reported having no friends outside their family units. Participant #4 explains that she tries not to let epilepsy hold her back in life but does remark that she feels “different” and wants to feel “normal”. When Mary went to college, she began realising she had become very dependent on her parents, and she then embarked on a challenging journey of seeking her independence from them. She makes an effort not to let epilepsy limit her, and aims to lead a normal life.

Lerato, on the other hand, says her parents and friends are very well-informed and treat her no differently to her peers or siblings. She has had a seizure in the past 12 months, but does not experience them frequently. She feels her life is as normal as that of her peers and siblings without epilepsy.

It is interesting to note that despite varying seizure severity in this group, social support appears to play an important role in affecting the participants’ view of themselves, and their perception of their limitations. The role of the family, or other influential members such as teachers and healthcare workers, is a key component to “felt” stigma. They act as “stigma coaches” and impose

their perceptions onto the person with epilepsy, who then internalises these feelings (Schneider & Conrad, 1980). Their attitude toward the diagnosis informs the patient's perception of the diagnosis (Link, 1987; Link et al., 1989). The most prominent dynamic is the relationship between a parent and a child who has epilepsy, which we observe in the majority of cases outlined above. In Mary's case especially, she reports on the resulting dependency her parents instilled in her from childhood (Schneider & Conrad, 1981; Williams et al., 2003). The child adopts an identity of being chronically sick (Jacoby, 2008). This "overprotection" of the child leads to a parent limiting the actions of the child in an attempt to "protect" him or her. Youths with epilepsy have shown to have lower self-esteem and higher rates of depression and anxiety (Baker et al., 2005). These restrictions then feed into adulthood and persons with epilepsy continue to limit themselves as a result of being conditioned (Jacoby & Austin, 2007). It is interesting to see the contrast in the participants' view of themselves, and their perception of their limitations. Patience and Participant #2 appear to conclude they are "different", and epilepsy limits them. Mary and Participant #4 appear to still be combating the issue that they feel "different" but are making an effort to lead normal lives, whereas Lerato reports feeling no different to her peers and siblings. However, social support should not be viewed in isolation, as other experiences may also have contributed to forming participants' perceptions, for example, community understanding and incidents of enacted stigma. This will be discussed under the next two sections.

6.2.1.2 Public Understanding

In recent years, significant effort has been made in combating epilepsy-associated stigma. The World Health Organisation (WHO), International Bureau of Epilepsy (IBE) and the International League Against Epilepsy (ILAE), launched a collaborative global campaign against epilepsy, titled "Out of the Shadows" in 1997 to educate people about epilepsy in order to promote positive attitudes toward people with epilepsy and to minimise epilepsy-associated stigma (Diop et al., 2003). This initiative has ignited further culturally-targeted interventions being taken to minimise epilepsy-associated stigma and discrimination against people with epilepsy (Carpio & Hauser,

2009). There has been a positive impact of these interventions and awareness campaigns in combating epilepsy-associated stigma in communities around the world (Ahmad, 2011). Participants in this research made several assertions regarding the public's understanding about epilepsy. Participants reflected on their hope that the public will learn more about epilepsy in order to avoid misinformation and ill-treatment towards people with epilepsy. Lerato explains that the reason she is able to live such a normal life with epilepsy is because her parents and peers are informed and educated about epilepsy. She indicates that if she grew up in an environment where the people around her believed it was witchcraft and devil's work, then she would be living a very different life with epilepsy. In the case of Mary, she reports how differently she and her father lived with the same disease as a result of growing up in very different environments. Mary reported being cautious about who she tells – she is open to telling people she has epilepsy, but only if she feels she will not be judged by them. Participant #5 explained that people judge you because they don't know anything about seizures, and Participant #4 also said her peers were too nervous to be around her in case she had a seizure and they weren't sure how to deal correctly with it. Participant #4 explained she wants people to speak out about epilepsy as she doesn't want to feel "different" from everyone else who is "normal" while she is not. Participant #3 explained how he had a very supportive mother and friends' group, and he wants people to know about epilepsy and know how to help if he has a seizure. His friends would help him disclose and inform others that he has epilepsy and that he is "okay". Lerato and Participant #6 shared these sentiments in that they disclose they have epilepsy and then they feel safe that people will know if they have a seizure. Lerato admitted that when she was first diagnosed, she didn't know what epilepsy was and referred to it as not a "normal disease" like diabetes, which is well known and understood. In addition, she concedes that, although people in her peers' circle are "informed" about epilepsy and don't treat her differently, they still hold erroneous beliefs and associate epilepsy with people only having a "violent" seizure where they violently shake and fall to the floor. The key theme that emerged was that if the public are informed and accepting of the disease, then people with epilepsy would not be a target for stigmatisation and have to

fear discrimination, and it would be safe to disclose that they have epilepsy.

Lerato, Mary and Participants #3, #4 and #5 were the youngest of the group with an age range of 19 to 34 years old (mean age of 26 years old) and as explained in the previous section (6.2.1.1 Social Support) they were all supported by caring families and well-informed health care professionals who were very involved in managing their epilepsy. They all showed the most progressive approaches in coping with their diagnosis by being willing to disclose their diagnosis and striving not to let epilepsy limit them. However, Mary and Participants #4 and #5 did also report experiencing acts of enacted stigma (which will be discussed in section 6.2.1.3 (Enacted Stigma and Fear of Enacted Stigma). Enacted stigma and fear of enacted stigma might have been expected to make them less likely to disclose their diagnosis out of fear of discrimination. Nevertheless, they felt confident about sharing their diagnosis with others, and this is likely to be due to the secure social support which they received, and which allowed them to develop coping skills. Perhaps this younger generation are slowly beginning to reap the benefits of epilepsy awareness campaigns as epilepsy becomes more accepted and understood.

Although global attention has been given to epilepsy-associated stigma and global efforts have been initiated to combat epilepsy-associated stigma, there is still a need for more effective targeted awareness campaigns. Keikelame and Swartz (2013a) highlight that in South Africa, there is a difference in cultural interpretations and understandings of epilepsy throughout the various communities, and therefore different forms of stigma are present in communities (Keikelame & Swartz, 2013a). From the group of participants in this research, we see varying levels of understanding in their respective communities. Lerato, who appears to struggle the least with any epilepsy-associated “felt” stigma, recognises that even those who are “informed” still hold incorrect understandings. Her parents explained to her that in some communities in their culture people believe epilepsy is witchcraft and devil’s work. Mary reports that her parents explain that some people have “silly” beliefs, for example that epilepsy is a “mental thing”. Large scale studies in

the UK (Jacoby et al., 2004) and USA (Austin et al., 2002) about the public perception of epilepsy show that misinformation still exists even in developed countries. These misbeliefs include that epilepsy is thought to be a mental health problem, that epilepsy is contagious and that PWE are likely to be frail, antisocial, violent and retarded. Some communities especially in developing countries which have a lack of access to healthcare resources and are still reliant on traditional healers, also still hold superstitious beliefs (Baskind & Birbeck, 2005; Mushi et al., 2011; Winkler et al., 2010).

Informing the public through awareness campaigns and distributing resources to communities which lack access to healthcare, will hopefully have a positive impact on creating informed environments for people with epilepsy. This would make people with epilepsy not a target for stigmatisation, and alleviate fears of discrimination by creating a safe space in which to disclose that they have epilepsy.

6.2.1.3 Enacted Stigma and Fear of Enacted Stigma

There were few reported cases of enacted stigma across the participants of this study. The cases that were reported occurred only in childhood. No incidences of enacted stigma were reported during adulthood. In this group, Mary, and Participants #1, #4 and #5 reported being stigmatised by others as a result of having epilepsy. Mary and Participant #1 recall that their peers, when they were children, would tease them and call them names. Participant #4 recounted how people stayed away from her because they didn't know how to handle her if she were to have a seizure. A study done in the UK suggested that social avoidance of people with epilepsy might be the result of fear of not knowing what to do if the person has a seizure (Robson, 2006). Participant #5 reported that people in the community would send their sympathies to her family about her diagnosis. Of all the participants, Patience appears to be the most crippled by the fear of enacted stigma, yet she has never experienced being directly discriminated against due to having epilepsy. She has witnessed HIV-positive people being the targets of stigma in her community and fears the same treatment. She explains that she fears people will laugh at her and that they won't see her as "equal" to them. Her fear of

being judged even extends to that of her husband. She remarks on how she does not want to embarrass him. Scambler and Hopkins' (1990) "hidden distress" model proposed that a majority of participants did not feel stigmatised due to having experienced an actual incident of enacted stigma, but rather that their "felt" stigma often preceded any acts of discrimination against them.

6.2.1.4 Reminders of Being "Different"

In this group of participants there were a number of daily reminders that confronted them and reminded them of their diagnosis. The key themes that emerged in this group, was the inability to drive a car, applying for a job, taking daily medication, attending a party, school selection and taking a bath. These daily reminders may act as reinforces of being "different" to their peers.

Mary explains her conundrum of driving a car. She chooses not to tell people to whom she gives lifts in her car that she has epilepsy, as she fears people will "freak out" and not want to drive with her. She goes on to explain that in the back of her mind she worries about having a seizure when driving. Participant #3 says he knows how to drive a car, but keeps it a secret. He doesn't want to be a danger to other people on the roads, and therefore does not drive. He chooses not to tell his friends he can drive, presumably because he doesn't want them to think he can't do something because of his epilepsy. He rather tries to normalise it by saying he doesn't know how to drive. Participant #4 spoke about how she always puts her diagnosis on her CV when she applies for jobs, but worries about how the employer will react. She fears they may not select her for the job because she has epilepsy. Participant #4 also spoke about not liking the feeling of "depending" on medication and therefore often skips her medication, presumably to feel "normal". In addition, Participant #4 spoke about not being able to bath alone in case she was to have a seizure in the bath and drown. Participant #1 and Lerato spoke about attending parties. Lerato explains how at her age it is common for everyone to go to a party and drink. However, her doctor says she shouldn't drink too much. Therefore, when she goes out to parties, she needs to control herself, which is conflicting with the behaviour of her peers at

this age and therefore may act as a reminder of being “different”. Participant #1 opted to withdraw from going to parties altogether. He said he no longer spends time with friends who drink as his doctor said he must not drink. Mary explained she needed to attend a special education school due to the effects of her medication – this led to her being teased by children in her community who used to call her “crazy”. This behaviour would have caused Mary to feel “separated” from the other children in her community. Patience believed she cannot “study with books” as she feels the stress causes her to have a seizure. She continually compared herself with “normal” people and was frustrated that they “could think” and she couldn’t.

The above daily occurrences and experiences of the participants are possibly daily reminders of being deemed “different” and may further impact on epilepsy-associated “felt” stigma, invoking a fear of loss of status and social exclusion due to being “different” because of having epilepsy.

6.2.1.5 Fear of The Next Seizure

The fear of not knowing when the next seizure might occur is worrisome for persons with epilepsy. They are worried that other people may see them having a seizure, or that something bad will happen to them during their seizure.

Participant #1 explained that he is worried about his safety if he has a seizure in public as he thinks that people may rob him. Participant #4 explained how she often is unable to enjoy herself as she is always thinking about “it”, and also expresses worry about her safety if she has a seizure. Participant #6 shared the same sentiments and actually stopped playing sports as she was concerned about having a seizure while playing sport. Patience explains how she tries to make quick visits to the shops as she fears she may get a seizure, and she doesn’t want anyone to find out that she has epilepsy. Mary explains how when she drives, she prays to the Lord as she fears she may get a seizure while driving. Lerato and Participant #3 explained that they choose to disclose that they have epilepsy as they want people to know what to do if they have seizures. People with epilepsy are likely to avoid situations that

would result in them being either hurt or embarrassed if a seizure was to occur. In this way, people with epilepsy often isolate themselves and withdraw from certain activities.

6.3 Impact of Epilepsy-Associated Stigma

There is substantial evidence indicating that epilepsy-associated stigma negatively affects people with epilepsy to varying degrees, and that the diagnosis of epilepsy goes beyond a clinical diagnosis to encompass a new social identity. This has an impact on their quality of life, marital status, employment status, education level, depression level, psychiatric level and anxiety level (Ahmad, 2011). Participants reported various ways that epilepsy-associated stigma had impacted on their lives. For example, Participant #6 indicated she stopped playing sports, Participant #1 indicated he stopped attending social gatherings, and Patience reported limiting how long she left the house, and that it stopped her from studying and getting a job. Participant #2 remarks how she would have been able to achieve a lot more in life if it wasn't for having epilepsy.

6.4 Strengths and Limitations of the Study

6.4.1 Strengths

The strengths of this study include: appropriate methods which collected rich in-depth data about the topic, participants who were well placed to answer and openly discuss issues around the topic, and lastly, a pilot study which provided a good foundation upon which to ground the next stage of research.

The use of a qualitative method, collecting data via semi-structured interviews, was a strength of this study as it yielded a rich source of information. Human behaviour, perceptions and emotions are not static, they are dynamic and complex.

Stigmatisation is a uniquely different experience for each individual as it is mediated by factors such as cultural values, education and legal rules, and therefore an ethnographic approach to explore and record a person's subjective experiences and perceptions is an appropriate method to employ. This approach opens the opportunity to be able to fully explore and represent a person's lived experience, by

capturing both the implicit and the explicit. This approach allows us to represent a person's experiences in as naturalistic a context as possible.

Participants were purposefully sampled through Epilepsy South Africa. This method was chosen as it is the most appropriate method to identify participants who can impart in-depth personal knowledge that will help to answer the research question. This involved the identification of people with epilepsy who were well-known to the organisation and were willing and able to articulate their experiences in a detailed and reflective manner.

Pilot studies in qualitative research are beneficial. In the context of ethnographic research, they enable the researcher to become familiar with fieldwork and enable the researcher to gather background information which can be used to guide the logistics and questions of the next stage of the research (Janghorban et al., 2014; Kim, 2011). The experience of the pilot study informed my approach and methods for the Master's research component.

6.4.2 Limitations

This is a qualitative study that tries to fathom the impact of having epilepsy on an unrepresentative number of individuals. Therefore, no generalisations are made to a larger group.

Furthermore, another limitation of this study is having only one interview per participant. A series of in-depth interviews per participant would have allowed more time to gain rapport and explore issues in more depth and uncover further personal reflection and feelings.

6.5 Recommendations

6.5.1 Future Awareness

From this investigation, the key areas which emerged, and indications of where future awareness should focus, is on raising public understanding of epilepsy, giving advice on parenting a child with epilepsy, and facilitating community support groups for people with epilepsy.

It is important to acknowledge the current infrastructure in place which provides assistance to people with epilepsy in South Africa. One of the leading NGOs helping people with epilepsy is Epilepsy South Africa. All participants for this research were identified through this organisation. Epilepsy SA's mission is to promote human rights and an inclusive society for persons with disabilities, primarily persons with epilepsy. Epilepsy SA has branches throughout South Africa and plays an active role in communities around South Africa. Epilepsy SA offers informative resources, counselling, support groups, epilepsy awareness management and training, protective workshops and income generation projects to people in South Africa with epilepsy (Epilepsy SA, n.d.[b]).

Interventions and awareness campaigns such as the World Health Organisation (WHO), International Bureau of Epilepsy (IBE) and the International League Against Epilepsy (ILAE), launched a collaborative global campaign against epilepsy stigmatisation called "Out of the Shadows". This campaign ignited further projects to combat epilepsy stigma and has had positive impacts on combating epilepsy stigma in communities. Therefore, there is a need to continue to promote targeted and culturally appropriate de-stigmatisation campaigns around the world and in South Africa and other less developed countries more specifically (Ahmad, 2011; Carpio & Hauser, 2009; Diop et al., 2003).

In addition to public awareness, public points-of-contact for people with epilepsy such as health clinics should have staff trained in the appropriate management of the psychosocial impact of epilepsy. This includes raising awareness through healthcare workers, teachers, first-responders and affected families. As explored in this dissertation, "stigma coaches" and social support appear to play an influential role in the adjustment of a person with epilepsy. Comparing Mary and Lerato, and how they experience living with epilepsy, show how different parenting styles in their childhood have had an impact on them. Lerato finds living with epilepsy very easy, whereas Mary has had to put in a lot of work to begin feeling confident in managing her life.

Support groups can offer a safe haven for individuals like Participant #2 and Patience, who feel very alone in facing their struggles of living with epilepsy. Visible support groups established in communities where stigma is high would allow people with epilepsy to meet other people living in their community with epilepsy and together spread awareness.

Lastly, a powerful tool for spreading awareness and providing inspiration to people with epilepsy is through respected public community figures who become advocates for living with epilepsy and are prepared to publicly speak about this. This is increasingly becoming a powerful tool-of-change (Engel, 2013). Patience's story of how she felt inspired when she found out that a respected and well-employed member of her church had epilepsy was an example of how role-models can inspire. Patience felt alone, and then this example made her believe that she too can lead a satisfactory life.

The overall aim of epilepsy awareness campaigns and interventions is to improve the "social value" of people with epilepsy, in order for them to live a "normal" life without stigmatisation.

6.5.2. Future Research

Further research across a variety of communities should be conducted in South Africa to explore in more depth the unique challenges faced in communities in South Africa. Investigations should be conducted to explore epilepsy-associated stigma across the socioeconomic spectrum, and between urban and rural settings, as these communities will likely experience both similarities and differences in the beliefs and types of stigma. In addition, surveys of the attitudes, beliefs and practices of low-tier healthcare workers and the broader public in general should be conducted. Lastly, an audit of the current resources available to people with epilepsy in South Africa should be done. Conducting further research will enable us more fully to understand epilepsy-associated stigma in the context of South African communities, and to implement targeted and culturally relevant awareness campaigns and interventions.

6.6 Conclusion

Not all people with epilepsy experience stigma; Jacoby and colleagues (Baker et al., 2001; Jacoby, 1992, 1994; Jacoby et al., 2001) revealed a linear relationship between epilepsy severity and “felt” stigma. Suggestions are that this linear relationship between epilepsy severity and stigma is mediated by other factors such as perception of limitations, education (Ryan et al., 1980), both professional and informal support (Suurmeijer et al., 2001) and medication side-effects (Baker et al., 1997). These mediating factors may explain why people who have well-controlled seizures may still experience “felt” stigma. However, for those who do experience stigma, there is a clear negative impact on their life, affecting domains such as: quality of life, marital status, employment status, education level, depression level, psychiatric level and anxiety level (Ahmad, 2011).

Epilepsy is unique in the level of stigmatisation it receives. Theory of social stigma defines stigma as an “undesired differentness” and refers to a loss of status and social exclusion of the stigmatised individual (Goffman, 1963). Diseases that are stigmatising often present with symptoms which are unfamiliar and are not therefore understood and create severe discomfort in social interactions. They also form part of the person’s identity and influence the perceived “social value” of the ill person (Albrecht et al., 1982; Crandall & Moriarty, 1995; Fabrega & Manning, 1972; Field, 1976; Reidpath et al., 2005; Rush, 1998; Weiner, 1993; Weiner et al., 1988). Public misperceptions due to a lack of understanding of epilepsy combined with visible symptoms, (i.e. seizures) which appear “violent” in nature are likely to be the basis for epilepsy-associated stigma. Epilepsy-associated stigma consists of varying forms of stigmatisation, including enacted, perceived (or “felt”) and courtesy stigma (Scambler & Hopkins, 1990) and occurs both at the institutional and individual level. Scambler and Hopkins’ (1990) “hidden distress” model proposed that a majority of people with epilepsy do not feel stigmatised due to having experienced an incident of enacted stigma, but rather that their “felt” stigma preceded any acts of discrimination against them, although possibly reinforced by later acts of enacted stigma. Public misunderstanding and “stigma coaches” impose their beliefs onto people with epilepsy, who in turn

internalise these feelings. Their attitude toward the diagnosis informs the patient's perception of the diagnosis (Link, 1987; Link et al., 1989; Schneider & Conrad, 1980).

The individuals recruited for this research were all from different backgrounds and communities and have experienced living with epilepsy through different lenses. They reported a broad range of subjective experiences and perceptions. There are both similarities and differences between them in their realities of living with epilepsy. Furthermore, the findings from these case studies mostly confirm the findings reported in the literature as discussed above.

This study found that, across all participants' experiences, the most impactful factors were the social support they received, the public understanding of the community they lived in, and having daily reminders of being "different" coupled with the fear of when the next seizure will occur. The carers of the participants played a significant role in helping them to adjust to a life of living with epilepsy, and the understanding of their community played a significant role in whether or not they were open about having epilepsy. Daily reminders and fear of when the next seizure will occur also contributed to their perception of feeling "different". The participants of this study reported withdrawing from activities, fearing discrimination, believing they had limited abilities, negative self-images, not having friends, and being teased.

This study revealed that the participants of this study, who were people living with epilepsy (recruited from communities in Cape Town, Western Cape, South Africa), experience epilepsy associated stigma. Therefore, a need exists for further research and awareness campaigns. The aim of epilepsy awareness campaigns and interventions should be to improve the "social value" and social identity of individuals living with epilepsy by addressing stigma and discrimination at all the levels at which it is experienced. This can be done through further in-country research and developing culturally relevant awareness campaigns.

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Appendix A

Consent form for participation in a Master's research project University of South Africa (UNISA)

You are invited to participate in an Master's research project conducted by UNISA student, **Emma Eastman**. The purpose of this research is to **investigate personal experiences of living with epilepsy, from people with epilepsy (PWE), in South Africa.**

Your participation

Your participation will involve being available for an in-depth face-to-face interview. The interview is estimated to take up to 2 hours. The interview will be recorded.

Risks and discomforts

There are no known risks associated with this research.

Potential benefits

This research may help us to understand how experiences of epilepsy can differ from each individual, and in so doing, provide a foundation to investigate possible interventions, which aim to improve the lives of PWE.

Protection of confidentiality

Your identity will not be revealed in any publication resulting from this project. All information provided in the interview will remain anonymous and confidential. The information gathered from the interview will only be used for research purposes.

Voluntary participation

Your participation in this research study is entirely voluntary. You may choose not to participate, and you may withdraw your consent to participate at any time. You will not be penalized in any way should you decide not to participate or to withdraw from this study.

Contact information

If you have any questions or concerns about this study or if any problems arise, please contact: Emma Eastman at +27 83 680 7980.

Consent

I have read this consent form and have been given the opportunity to ask questions. I give my consent to participate in this study.

Participant's signature: _____

Date: _____

A copy of this consent form will be given to you.